

Transition to Long Term Mechanical Ventilation: The Lived Experience of Individuals
with Chronic Respiratory Failure and their Family Caregivers

By

Winnifred Briscoe

A Thesis Submitted to the Faculty of Graduate Studies in Partial Fulfillment of the
Requirements for the Degree of

MASTER OF NURSING

Faculty of Nursing
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MASTER OF NURSING

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ABSTRACT

Growing numbers of children and adults with chronic neurological and respiratory disease, survive respiratory failure because of their use of long-term mechanical ventilation (LTMV) systems. Concurrent with increased utilization of such systems are escalating operational, economic and ethical challenges to health care systems. Consequently, there is growing impetus to develop fiscally responsible programs able to meet the distinct needs of this population. To date, much of the research focus pertaining to the utilization of long term ventilation has been on the efficacy of a range of respiratory technologies, the physiological and functional outcomes of intervention, and the quantitative measurement of quality of life. Studies that explore the perspectives of individuals with chronic respiratory failure and their family caregivers are also warranted. Accordingly, this phenomenological study, informed by the philosophical tenets of Heidegger (1927/1962), explored the lived experience of transition to LTMV.

Mechanically ventilated participants were recruited from a respiratory outpatient clinic and a long term care facility in western Canada. Family caregivers of ventilator users were also invited to participate. Twenty-seven in-depth, semi-structured interviews of 11 ventilated individuals and seven family caregivers were carried out over a four month period. Interviews explored ventilated participant's recollection of what it was like to transition from spontaneous breathing to the stable reliance upon mechanical ventilation. Separate interviews with family caregiver's explored their memories of being with a ventilated family member during transition to LTMV. Demographic information, health survey data (SF12v2), and field notes were also recorded. Both the interview and

field note data were transcribed, read and re-read and analysed according to the method developed by van Manen (1990).

The data analysis revealed the essence of ventilated individuals' lived experience of transition to LTMV as a process of *sustaining self*. For ventilator users, five themes characterized this essence: (1) Tyranny of symptoms, (2) Self in peril, (3) Awakening to a paradox, (4) Struggling for autonomy and (5) Life goes on with a reclaimed self. The essence of the family caregivers' lived experience was *sustaining family*. Five themes characterized the essence of the experience as follows: (1) Intrusion of symptoms, (2) Being there, (3) Bridging two worlds, (4) Making peace with the ventilator and (5) Life goes on with new vigilance.

Similarities and differences between ventilator user and family caregiver experiences and health survey scores are presented. Participant's advice for both family caregivers and individuals with chronic respiratory failure is outlined, as are recommendations for health care professionals and individuals living with CRF.

In summary, study findings provide nurses and other health professionals with understanding and knowledge about what it is like to transition to LTMV, thereby providing a foundation for holism in the care of individuals with chronic respiratory failure. Understanding of client and family perspectives is also an essential component of comprehensive, patient-centred, program development. Findings from this study serve as a basis for several recommendations relating to nursing practice, education and research.

DEDICATION

This thesis is dedicated, with great respect, to all individuals and families who experience transition to long term mechanical ventilation, and to the 18 individuals who, very generously, shared their stories for this study. In particular, I wish to dedicate this work to the memory of Lisa, who was a gentle, kind and benevolent spirit. I was very grateful to have reconnected with her in the weeks prior to her death. Her story was with me as I read and “lived” the stories of those who participated in this study.

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List of Abbreviations

Full Term	Abbreviation
Acute respiratory failure	ARF
Bi-level positive airway pressure	BIPAP
Chronic respiratory failure	CRF
Continuous positive airway pressure	CPAP
Health related quality of life	HRQOL
Intensive care unit	ICU
Intermediate intensive care unit	IICU
Long term care	LTC
Long term mechanical ventilation	LTMV
Mechanical ventilation	MV
Negative pressure ventilation	NPV
Non-invasive ventilation	NIV
Partial pressure of arterial carbon dioxide	PaCO ₂
Partial pressure of arterial oxygen	PaO ₂
Quality of life	QOL
Respiratory intensive care unit	RICU
Respiratory outpatient clinic	RSOPD
Ventilator assisted individual	VAI

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CHAPTER ONE: INTRODUCTION

Background

The incidence of respiratory failure escalated in the 1950s as the ravages of the poliomyelitis epidemic took their toll. Prior to that time, respiratory failure was usually synonymous with death (Villar, Mendez, & Slutsky, 2001). Health care communities in the developed world responded to polio related respiratory failure by implementing negative pressure respiratory devices, known as iron lungs. Subsequent development of positive pressure ventilation systems, combined with tracheotomy, resulted in a significant reduction in mortality rates from bulbar polio (Goldberg, 2002). As a result of those initial efforts and innovations, intensive care units (ICU) were established, and respiratory medicine and nursing were advanced, facilitating the innovation and testing of many mechanical ventilation technologies, long-term systems among them (Villar et al., 2001).

Today long-term mechanical ventilation (LTMV) technologies are utilized to support growing numbers of children and adults with chronic respiratory failure (CRF) originating from diverse disease conditions including, but not limited to: muscular dystrophy, amyotrophic lateral sclerosis, spina-bifida, spinal muscular atrophy, post-polio syndrome, central hypoventilation syndrome and spinal cord trauma. Historically, individuals who required LTMV were cared for in intensive care units (ICU), where they often required a disproportionate amount of cost, relative to other ventilated persons, because their stay was usually prolonged (Bach, Intinola, Alba & Holland, 1992; Cook, Meade, & Perry, 2001; Goldstein, Psek, & Gort, 2005; Make et al., 1998; Sevick, Kamlet, Hoffman, & Rawson, 1996). Consequently there was, and continues to be, growing impetus to resituate long-term ventilator-assisted individuals (VAI) to points of

care other than the ICU (Brooks, De Rosie, Mousseau, Avendano, & Goldstein, 2002; Donat & Hill, 2003). As care for individuals requiring LTMV is evolving, gaining a broad understanding of all issues pertinent to this distinct population is vital.

Fundamental to such understanding is an awareness of the perspectives of ventilator users and their families.

Statement of the Problem

Common to all long-term ventilator users' experience is a period of transition from spontaneous breathing to the stable utilization of LTMV. Transition often occurs over an unpredictable timeframe, and within a number of healthcare environments. Individuals new to the utilization of LTMV eventually reside in their home, an assisted living community, or a long-term care facility; however, the interval of time between their initial experience of respiratory failure and their eventual adjustment to a home environment may be characterized by both physiological and psychological struggle.

Moreover, individuals with chronic respiratory failure (CRF) often have concerns related to mobility, independent living, stigma, and social isolation. In addition, they may also experience uncertainty regarding the progressive nature of their primary disease and the potential for complications. Family caregivers may also be confronted by multiple challenges during the period of transition.

Collectively, all of these factors bring into being a complex patient care situation that challenges both the health care system and the nurse's capacity to provide comprehensive, patient-centered care. Nurses should, therefore, be supported by a system that facilitates the acquisition and integration of best evidence for the care of these

individuals and their family. Such evidence requires knowledge and understanding of user and family perspectives.

While prior studies have looked at many aspects of living at on home mechanical ventilation (Brooks, Tonack, King, Simson & Goldstein, 2002; Fitch & Ross, 1998; Lindahl, Sandman, & Rasmussen, 2003, 2005, 2006; van Kesteren, Velthuis, & van Leyden, 2001), to date there is very little published data concerning the distinct needs of the hospitalized ventilator user who will not wean from assisted ventilation, but who will require LTMV. There are no published studies exploring the process and experience of transition to LTMV from the perspective of the ventilator user, or the informal family caregiver. In addition, the voices of ventilated individuals residing in LTC facilities have yet to be heard.

While evidence for the care of these populations is often extrapolated from the evidence for care of other patient and family populations, studies that explore distinct phenomena, about which little is known, are essential. Understanding phenomena from the perspectives of those who actually experience them is a significant goal for nursing. Qualitative research methodology, and phenomenology in particular, is appropriate for this purpose as “phenomenology aims at gaining a deeper understanding of the nature or meaning of our everyday experiences” (van Manen, 1990, p.9). When nursing research provides understanding of the human response, and lived experience, it advances nursing practice and facilitates the discovery and innovation of interventions targeted to better serve those in our care (Wilson & Hutchinson, 1991).

This study provided a detailed description of the experience of transition to LTMV from the “*emic*” or insider perspectives of both the VAI and the family caregiver. Such

description serves to inform those caring for individuals transitioning to LTMV, by enhancing their understanding of the lived experience.

Purpose and Objectives

As little is known about the experience of transition to LTMV, the purpose of this qualitative, phenomenological research study was to discover the subjective meaning of the living of the experience of transition in order to gain an in-depth understanding of both individual and caregiver perspectives. The questions guiding this study were:

- (1) How do individuals with chronic respiratory failure experience transition to LTMV?
- (2) How is transition to LTMV experienced by family caregivers?
- (3) What are the similarities and differences in the meaning of the transition experience for individuals with chronic respiratory failure and their family caregivers?

Assumptions and Preliminary Work

My experience as an intensive care nurse has provided me with understanding of what it is like to care for critically ill persons and their families. Nurses, working within a critical care culture, provide care to individuals who readily recover from devastating injury and life-threatening disease; however, they also care for growing numbers of individuals who survive critical illness with chronic complications, some of whom require lifelong technological support such as hemodialysis or mechanical ventilation.

Within a fast-paced, acute care setting, the care of the latter patient population is sometimes viewed as being less readily gratifying nursing work. My interest in individuals who require LTMV initially stemmed from a broader concern for the

chronically-ill ICU patient. What is it like to be increasingly aware of one's ICU surroundings, yet too ill, or too dependent upon technology, to leave? What was life like after finally leaving the ICU?

In the ICU, the chronically-ill individual finds him/herself in a world possessed by frenetic energy, illuminated by fluorescent light, and humming with the noise of machines (Donchin & Seagull, 2002). Physiological progress is often measured in small increments and frustration and setbacks are all too common. The lives of family members and family caregivers become entwined with the struggles of their loved one, and sustained support and ongoing encouragement by health care providers is essential.

Often, individuals transitioning to LTMV commence their hospitalization and their journey of transition within an ICU environment. Transition is a process that occurs over a long time and within a number of health care settings, consequently an individual nurse may only experience a part of the whole transition process. As a result, the ICU nurse is not always aware of the long-term outcome of the ventilated patient's struggles. My experience as an ICU nurse, and my questions about the chronically-ill client, served as motivation for my engagement in a six-month practicum course, which facilitated the comprehensive exploration of many issues pertaining to LTMV.

During that time I was involved in many informal discussions with persons utilizing LTMV, including respiratory clinic attendees, independent residents living in the community, and long-term care facility residents. Ventilator assisted individuals and their family members readily engaged in conversation and shared personal stories about their lives, including anecdotes about their experiences of transition to LTMV.

As a teacher and a clinical nurse specialist, I saw the transition phenomenon through a somewhat broader lens and I continued to observe and think about the unique transition that was undertaken by individuals with chronic respiratory failure on long term ventilators. For the individual with CRF, the period of transition appeared to be one marked by both physiological and psychological struggle. Such struggle understandably challenged the patient and family; however, it has been my experience and observation that the process also challenges health care providers. During my practicum experience, nurses and other health professionals expressed the view that caring for an individual transitioning to LTMV was an “emotionally draining experience”.

I believe that care for the chronically-ill patient and their family presents a distinct challenge for ICU nurses, and others, who care for individuals throughout their critical illness trajectory. The challenge exists, not only because of the requirement for advanced technological expertise, but because the care experience may be particularly imbued with one’s own perceptions and perspective of what it means to be alive and struggle and suffer.

It is my view that enhancing our understanding of lived experience serves to assist nurses in their ongoing efforts to provide patients and families with comprehensive and compassionate care. Furthermore, it is my view that such knowledge aids health care professionals in gaining a better understanding of themselves, one another and their professional care giving encounters. Such knowledge is essential to effective interdisciplinary and patient-centered collaboration and it may also inform the efforts of those who seek to support nurses and other health professionals in achieving excellence and longevity in their work.

My preliminary work served to reinforce my view that it is important for nurses, and others who care for those with chronic respiratory failure, to acquire a greater understanding of what it is like to transition to LTMV and live a life on LTMV.

Assumptions and definitions of major constructs

Assumptions for this research study were based upon philosophical beliefs grounded within the qualitative research paradigm and naturalistic inquiry, and beliefs concerning transition and family caregiving that stem from core concepts of interest to the discipline of nursing, which are derived from and related to the basic metaparadigm concepts of person, environment, health and nursing (Chick & Meleis, 1986; Creswell, 1998; Fawcett, 1995; Kralik, Visentin, & van Loon, 2006; Morse & Field, 1995; Munhall & Boyd, 1993; Schumacher & Meleis, 1994; Travis & Piercey, 2002; van Manen, 1990).

Assumptions include:

- (1) There are multiple knowable realities and human phenomena are best understood by viewing them as a whole and in context.
- (2) Researchers interact with the participants of the study to obtain data; inquiry changes both researcher and participant; and knowledge is both context and time dependent.
- (3) Health and illness transitions are experienced by an entire family, including those individuals who identify as being informal family caregivers.
- (4) VAI and family caregivers are experts in describing their experiences of transition.

Definition of Major Constructs

For the purpose of this study, major constructs were defined as follows:

Interpretation or "To interpret"

Interpretation brings out the meaning embedded in narrative text through a process that aims at explicating the essential structure or essence of the experience (van Manen, 1990). Interpretation is both an act of imagination and logic. It entails perceiving importance, order, and form concerning the phenomenon of interest that relates to the story narrative that is continually undergoing creation (Peshkin, 2000).

Meanings

Meanings refer to ventilator user and family caregiver experiences of living the transition to LTMV; their subjective appraisal of the transition experience and the evaluation of its effect on their lives (van Manen, 1990). Meanings may be positive, neutral or negative (Schumacher & Meleis, 1994). Knowledge is established through interpretation of the meanings attached to the experience of transition. (Coll & Chapman, 2000).

Understanding or "To understand"

Interpretation of a narrative text is to come to understand the possibilities of the text as they are revealed. Understanding is aimed at "grasping" what has been interpreted in a text (van Manen, 1990, p.180).

Transition or "transition to" or "transitioning"

Individuals undergo transition (are transitioning) when they need to adapt to new situations or circumstances in order to incorporate the change event into their lives (Kralik et al., 2006). "Transition to" connotes movement from one state to another, over time.

Family care giving, caregiver

Family caregivers are “kin or non-kin individuals” who provide both functional and affective unpaid assistance to an individual who is transitioning to LTMV and with whom a long-term or life-long commitment exists (Travis & Piercy, 2002, p.233). Family caregiving involves the provision of uncompensated care, predominantly in the home setting, involving significant amounts of time and energy for months or years, requiring the performance of tasks that may be physically, emotionally, socially, or financially demanding (Biegel, Sales, & Schulz, 1991).

Chapter Summary

Chapter one provided an overview of the rationale for research regarding VAI and family caregiver lived experience of transition to LTMV. There has been no published research exploring the transition experiences of individuals with CRF requiring LTMV. Similarly, there has been little published about the caregiver experience of being with a VAI as they transition through the trajectory from respiratory failure to the stable reliance on LTMV. In addition, studies that include the perspectives of ventilated persons who reside in LTC are required. As increasing numbers of individuals survive chronic respiratory failure, and rely on LTMV for survival, it stands to reason that a greater understanding of all aspects of care will be required in order to promote positive, client-centered intervention and program development.

CHAPTER TWO

LITERATURE REVIEW

Introduction

Chapter two will review the literature that established a foundation upon which to explore the phenomenon of transition to LTMV. In quantitative research, extensive review of the literature is undertaken in order to development a hypothesis. This is not the case for qualitative research; in fact, qualitative researchers have described the review process as potentially “presenting a quandary” (Patton, 2002, p.226). Qualitative researchers concern themselves with the notion of the literature review as a vehicle for potential bias and diminished openness to data as it emerges (Munhall, 1994; Patton, 2002).

However, in phenomenological inquiry it is generally considered necessary to review the literature concerning both the philosophical underpinnings of the methodology, and the phenomenon of interest, in order to obtain a good description of what is current in the literature, and to also establish a clear sense of what is to be studied, and how it will be studied. (Creswell, 1998; Munhall, 1994). Discussion of methodology and the procedural strategies that were implemented to reduce researcher bias are presented in chapter three.

In this study, the review of research concerning LTMV included: an examination of the utilization of LTMV within the context of chronic respiratory failure and related outcomes that have been measured to date, and an exploration of quality of life (QOL) for ventilator users and informal caregivers of individuals with chronic illness, including

those who care for ventilator assisted individuals. Lastly, an overview of the theory of transition in chronic illness is provided.

Respiratory Failure

The ventilator may facilitate respiration for persons under a variety of circumstances, most of which are temporary or short-term. For example, in acute respiratory failure (ARF) the ventilatory or gas exchange abilities of the respiratory system fail because of disordered processes within the lung or other organ systems (Cook et al., 2001). The individual with ARF requires ventilatory support, usually for a short time, until the cause of the acute failure is resolved or the patient dies (Make et al., 1998).

The literature lacks a definitive consensus as to what period of time defines a short, versus long duration for MV; however, the American College of Chest Physicians Consensus Document (Make et al., 1998) defined a patient who requires greater than four consecutive weeks of MV as a chronic ventilator-dependent patient. More recently, Make (2001) suggests that a long-term ventilator-assisted individual is defined as: "A person who requires mechanical ventilatory assistance for more than six hours a day for more than three weeks after all acute illnesses have been maximally treated and in whom multiple weaning attempts by an experienced respiratory care team have been unsuccessful" (p.3).

Ultimately, many chronic ventilator-dependent patients will be liberated from MV; however, some individuals may continue to require LTMV for their survival: the literature refers to this population as the chronically critically ill (CCI) (Cook et al., 2001; Dasgupta, Rice, Mascha, Litaker, & Stoller, 1999; Nelson, Kinjo, Meier, Ahmad, & Morrison, 2005).

Somewhat distinct from ARF and CCI is chronic respiratory failure (CRF), which refers to respiratory failure that is the result of irreversible and/or progressive disease affecting ventilation and gas exchange. Broad categories of conditions resulting in CRF include central nervous system disorders wherein control of breathing is affected, neurological disorders affecting respiratory muscle function, spinal cord trauma, skeletal disorders affecting thoracic wall function, congenital disorders of the upper or lower respiratory tract, complications of acute lung injury, infectious pneumonias, fibrotic lung disease, and cystic fibrosis (Make et al., 1998). While persons with CRF often experience episodes of reversible ARF, it is the chronic and progressive nature of their underlying disease that ultimately prohibits the maintenance of spontaneous ventilation. In contrast to ARF, CRF is usually characterized by a gradual decline in respiratory function, which is often accompanied by symptoms including fatigue, headache and dyspnea.

Chronic Respiratory Failure

CRF, sometimes referred to as alveolar hypoventilation or type two respiratory failure, is a common end-point of many diseases affecting the lung, chest wall or neuromuscular system (Martin & Sanders, 1995; Gribbin, 1993). Carbon dioxide (CO₂) is a by-product of metabolism, and is continually produced by cells within the body. CO₂ diffuses out of the blood into the lungs and is normally expelled during expiration. In normal individuals, elevated arterial partial pressures of CO₂ (paCO₂) result in an increased neurological stimulus to respiratory muscles, increased respiratory muscle effort, and improved expiration of CO₂ (Martin & Sanders, 1995). This predictable response maintains PaCO₂ levels within a normal range or a 'steady-state'.

In CRF, however, steady-state paCO_2 is no longer maintained due to the irreversible pathophysiological effects of the underlying disease process. A chronically inadequate response by the ventilatory pump and chronic elevations in paCO_2 levels are a hallmark of CRF.

Nocturnal elevations of PaCO_2 often precede diurnal elevations, as sleep normally alters a number of anatomical and physiological respiratory mechanisms, resulting in transient decreases in respiratory effort (Martin & Sanders, 1995). The individual with chronic respiratory disease cannot tolerate episodes of diminished respiratory effort, and chronic nocturnal elevations of PaCO_2 often manifest in the symptom of a morning headache (Gribbin, 1993). Chronic elevations in PaCO_2 also result in the manifestation of a number of other symptoms.

Excess CO_2 in the alveoli and blood prohibits normal gas exchange, resulting in a diminished oxygen tension (PaO_2) in the blood. This reduces the oxygen supply available for cellular activity and contributes to the symptom of fatigue. In addition, an inability to meet activity-related increases in O_2 demand results in the symptom of decreased activity tolerance. Additional symptoms of CRF may include daytime hypersomnolence, sleep disturbance, and altered mentation; all of which may result in the behavioural adaptation of a sedentary lifestyle (Martin & Sanders, 1995). The only treatment for chronic alveolar hypoventilation or CRF is mechanical ventilation (Martin & Sanders, 1995; Gribbin, 1993).

Over the last decade, published literature on LTMV reflects increases in both the incidence of CRF and the prevalence in utilization of LTMV (Appierto et al., 2002; Chu et al., 2004; Faroux, Boffa, Desguerre, Estournet, & Trang, 2003; Jardine, O'Toole,

Paton, & Wallis, 1999; Lloyd-Owen et al., 2005; Midgren et al., 2000). These increases are attributed to a number of factors including improved survival of neonates, children and adolescents with respiratory conditions; decreased mortality in critically ill populations; advances in respiratory technology; the increasing utilization of non-invasive ventilation and a shift in societal expectations for patients with chronic disorders (Corbett, 1998; Nierman & Nelson, 2002; Simonds, 2003b). Children born today with “chronic or disabling health conditions are expected to live more than 20 years”, and on this basis, “in the U. S., an estimated 500,000 children with special healthcare needs will turn 18, each year”(Reiss & Gibson, 2002, p. 1308). Many of these children will grow into adulthood and ultimately require ventilator support.

In the United States, an estimated 12,000 people were on LTMV in 1996 and care for these persons accounted for 2.3% of the U.S. healthcare budget (Ankrom, Barofsky, Georas, Zelesnick, & Greenough, 1998, p.309). There is very limited published data from Canadian sources regarding the incidence of CRF and prevalence of LTMV. In 1992, Litwin, Flegel and Richardson published an overview of home mechanical ventilation in Canada. They identified 283 persons on home mechanical ventilation and of those, 84% were over the age of eighteen years. They further reported an increase of 21% in the number of home mechanically ventilated persons during the year of their study. They identified that their numbers were approximate and it is significant that they also recognized that many VAI continued to reside in hospitals at that time.

In 1996 Dhillon, Frewen, Singh, and Speechley carried out a descriptive Canadian study of children who were dependent on LTMV at home. They identified 82 children between the ages of 44 weeks and 18 years of age and reported that neuromuscular

disease was the most frequently reported cause for respiratory failure. Furthermore, they acknowledged limitations in their study that may have resulted in an underestimation of the prevalence of LTMV, and they recommended that a national registry be developed in order to facilitate resource allocation planning, and outcomes measurement. Similar recommendations have been discussed in the literature from both Europe and Asia (Chu et al., 2004; Kamm, Burger, Rimensberger, Knoblauch, & Hammer, 2001; Midgren et al., 2000).

In Manitoba, the Winnipeg Regional Health Authority (WRHA) eligibility document for Adult Long Term Ventilation indicates that in 2000, approximately “56 persons were on LTMV as adults, compared to 29 persons in 1990”, and that the “yearly rise has been steady” (Mink, Corne, Giannouli, & Wells, 2002, p.13). The document reflects the use of invasive ventilation but is lacking similar description of the current use of non-invasive MV. Increasingly, adult programs may become responsible for a double cohort of individuals: those experiencing the initial transition to LTMV, and others already on LTMV who are transitioning from paediatric care. This may have ramifications for the operational structure of LTMV programs.

While recognizing that the number of persons transitioning to LTMV may be low and represent a minority of those on mechanical ventilation in the ICU and intermediate care areas, it is also important to recognize that these individuals require a disproportionate amount of costs because their hospital stay is usually prolonged (Cook et al., 2001; Make et al., 1998). Increased incidence of respiratory failure has placed increased demands on ICU units (Cook et al., 2001; Dasgupta et al., 1999; Make et al., 1998).

Mechanical ventilation (MV)

Mechanical ventilation provides the delivery of air, by volume or pressure to the lungs via an endotracheal tube inserted through the mouth or nose, a tracheotomy tube inserted through a surgical opening in the neck or, non-invasively, via a tightly sealed nasal mask, face mask, mouthpiece, or negative chest pressure device. MV is not the same as oxygen therapy. Although a ventilator may deliver concentrated oxygen to the lungs, its primary function is the treatment of respiratory failure. Oxygen therapy serves only to increase the oxygen tension available for gas exchange.

Negative pressure ventilation (NPV)

Negative pressure ventilation devices were utilized during the poliomyelitis epidemic in the 1950s. Since that time, new negative pressure technologies have been designed and implemented. Such devices facilitate the entry of air into the lungs by applying intermittent negative pressure to the chest and abdomen via a chest shell, a body jacket or cuirass (Baydur et al., 2000; Simonds, 2003b; Sunnerhagen & Grimby, 2001).

Review of all modes of non-invasive ventilation (NIV) revealed that NPV is utilized less frequently than other methods of NIV, due to a number of factors including lack of participant adherence (Turkington & Elliott, 2000). More recently a review of home ventilator users by Simonds (2003b), found that only 29% of persons using negative pressure devices reported a favourable outcome of improved sense of wellbeing and independence, compared with 67% of persons receiving positive pressure ventilation. As a result, adherence was an issue and many persons chose to discontinue their use of NPV (p.39). Baydur et al., (2000) reviewed 46 years of NIV use. They report a greater number of hospitalizations and respiratory infections in individuals with polio-related

respiratory failure who used NPV, when compared with those who used other forms of NIV. NPV has been implicated in upper airway collapse and increased frequency of episodes of aspiration (Baydur et al., 2000).

Duiverman, Bladder, Meinesz and Wijkstra (2005) reviewed a 48-year experience of care for LTMV persons with restrictive pulmonary disease. Their findings indicate that NPV could be effective in treating CRF; however, it was being utilized less frequently than non-invasive ventilation (NIV) because it was found to be more cumbersome to use. Corrado and Gorini (2002) reviewed studies of NPV and concluded that over the last decade, NPV has been “largely supplanted by mask NIV” (p.194).

Non-invasive ventilation (NIV)

Non-invasive ventilation is defined as ventilatory support that does not bypass the patient’s upper airway. NIV was initially introduced in the 1980s, for patients with nocturnal hypoventilation (Kerby, Mayer, & Pingelton, 1987). Studies exploring the increasing utilization of LTMV have attributed a substantial portion of that growth to the use of improved NIV systems (Adams, Shapiro, & Marini, 1998; Cheifetz, 2003; Evans et al., 2001; Goldberg, 2002; Jardine, O’Toole, & Wallis, 1999; Simonds, 2003b). When compared with invasively ventilated patients, there are important advantages of NIV: The absence of an artificial airway may decrease the incidence of nosocomial pneumonia, and in some hospital settings, patients with NIV are safely cared for in units other than intensive care, thereby conferring decreased financial cost (Bach & Wang, 1995; Cheifetz, 2003; Corrado et al, 2002; Evans et al., 2001; Make et al., 1998). In addition, tracheostomy may be perceived as disfigurement, and is associated with speech

difficulties, and potential complications including tracheal stenosis and tracheomalacia (Martin & Sanders, 1995).

NIV need not be delivered continuously to be effective, thus it is often initiated electively, and offered earlier in the progression of CRF (Bach & Wang, 1995; Baydur et al., 2000). Disadvantages of NIV include leaking of volume from the mask, or from the mouth when a nasal mask is employed (Evans et al., 2001). Tissue necroses over the bridge of the nose, inadequate humidification, and difficulty expectorating secretions have also been reported (Evans et al., 2001).

Non-invasive ventilation may be applied using pressure generators or volume preset ventilators (Evans et al., 2001). Settings provide continuous positive airway support (CPAP), or bi-level pressure support (BIPAP), which allows positive airway pressure to vary with inspiration and expiration. To date, utilization of NIV is varied among medical specialties and differs with respect to its frequency and location of use (Bach & Wang, 1995; Burns et al., 2005). Newer NIV technologies, responsive to a greater variety of ventilatory challenges, continue to be developed and trialed (Evans et al., 2001; Lloyd-Owren et al., 2005; Nava, Navalesi, & Conti, 2006).

Phrenic pacing

Normally the phrenic nerve stimulates diaphragmatic contraction. In persons with cervical spinal cord injury, electrodes may be internally implanted within the chest cavity in order to stimulate the phrenic nerve via an electronic pacing device. Stimulation results in diaphragmatic contraction, the generation of negative intrapleural pressures, and inspiration. This technology is limited to those individuals with spinal cord injury and

requires concurrent use of airway clearance strategies and technology (Howard & Davidson, 2003).

Invasive mechanical ventilation

Some cases of respiratory failure cannot be adequately managed with NIV due to persistent failure of airway maintenance or because NIV fails to adequately treat the respiratory failure (Baydur et al., 2000; Martin & Sanders, 1995). In these situations the implementation of invasive mechanical ventilation, via a tracheostomy tube, may be required.

Ventilators employed for long-term use differ from ventilators employed in the ICU. Most long-term ventilators are small, less complex, and provide fewer options for ventilatory settings than those employed in the ICU; thus they require greater patient stability prior to their implementation. Ideally, patients utilizing these ventilators are stable on room air and do not require additional oxygen. Newer models of long-term ventilators offer greater flexibility in their ventilator settings. Evolving technologies may continue to challenge financial resources as they may have the capacity to serve wider populations of patients with respiratory disease, and they may also cost more than traditional systems (Kurtzweil, 1999).

Quality of Life

Ventilated individuals

With increasing numbers of individuals suffering chronic illness, the healthcare system has been required to shift its focus from a primary concern with cure and quantity of life, to a focus that also includes quality and enhancement of life (Addington-Hall & Kalra, 2001; Schirm, 2002; Sullivan, 2002). Literature review of research concerning

quality of life (QOL) reveals an ongoing debate concerning the appropriateness and accuracy of study methodologies and measurement instruments (Arnold et al., 2004; Bernheim, 1999; Gill & Feinstein, 1994). Nevertheless, the literature also provides substantial evidence of growing recognition that the patient's own assessment of their health is a valuable outcome measure in the management of chronic illness (Simonds & Elliot, 1995; Simonds, 2003b; Sullivan, 2002).

Self-assessment of health and quality of life (QOL) are particularly relevant when exploring the effects of the utilization of life-sustaining technologies, such as mechanical ventilation (Simonds, 2003a). The primary goal for treatment is to restore or maintain health, therefore gaining a comprehensive understanding of the burdens as well as the benefits of treatment is important for health professionals, clients and caregivers. The following review explores the research pertaining to QOL for those with chronic respiratory disease requiring mechanical ventilation. In addition, QOL for the family caregiver of persons with chronic illness, CRF and LTMV is discussed.

Quality of life is a descriptive term that refers to an individual's wellbeing (Schirm, 2002). Assessment of the domains of emotional, social and physical wellbeing, including the ability to function in the ordinary tasks of everyday living, is generally accepted as being fundamental to QOL measurement (Bernheim, 1999). Health-related quality of life (HRQOL) is a term that seeks to describe the effect of disease processes and treatments upon QOL. The World Health organization included cultural aspects in HRQOL and provide the following definition, which requires an appraisal of QOL to be filtered through the individual's own perspectives: "individuals perception of their position in life in the context of the culture and the value system in which they live and in

relation to their goals, expectations, standards and concerns” (Kuyken et al., 1995, p. 1405).

Since various operational definitions of HRQOL exist, investigators define and measure domains differently; therefore findings must be carefully interpreted within the context of each research report. This is particularly true when reviewing studies of long-term ventilator users, as tools are often generic rather than disease-specific, samples are likely to be small and heterogeneous; and systematic evaluation has only occurred in recent years (Turkington & Elliott, 2000). Several different methodologies and instruments have been used to measure and report on aspects of QOL, HRQOL, global QOL, satisfaction and perceived health status for ventilator users.

Janssens (2001) reviewed the current use of tools to measure HRQOL in individuals with chronic lung disease. The utilization of generic measurement tools has provided investigators with a means to compare scores between various medical conditions. However, generic tools are not usually able to discriminate individual changes within a specific disease group. Therefore, disease specific tools have been recommended for the purpose of evaluating changes in HRQOL, within a given group. Janssen suggests, when undertaking clinical trials, in order to comprehensively assess HRQOL, investigators should employ both a disease-specific and a generic HRQOL tool. The choice of a HRQOL instrument must take into account the validity, reliability and responsiveness of the tool to the specific population of interest. To date, disease specific tools, including the chronic respiratory questionnaire (CRQ) (Guyatt, 1987) and the St. George’s Respiratory questionnaire (SGRQ) (Jones, 1991) have been most widely employed in those with chronic airway disease, and several other tools have been

specifically validated for use in persons with asthmatic disease. Only recently have tools been developed to specifically measure HRQOL in persons utilizing MV.

The Italian Maugeri Foundation Respiratory Failure Questionnaire (MRF-28) (Carone et al., 1999) has been employed in individuals with obstructive airway disease as well as in those with kyphoscoliosis, requiring MV (Janssens, 2001). Windisch et al. (2003) have recently developed and tested an instrument to measure HRQOL in persons on LTMV. They tested its psychometric properties following a clinical trial that included 226 home ventilator users in Germany. Concurrent validity of the tool was tested by correlating its scales with those of the Short Form-36 health questionnaire (SF-36) (Ware, 1993). The tool was found to discriminate amongst diagnostic groups of individuals with CRF. Despite the recent development of such tools, generic instruments including the Nottingham Health Profile (Hunt, McKenna, McEwen, Williams, & Papp, 1981) the Sickness Impact Profile (Bergner, 1976), and the SF-36 (Ware, 1993), have most often been employed to assess QOL for individuals using MV.

To date, the majority of participants in studies of long-term ventilation have resided in their home or a community-living facility (Brooks et al., 2004; Glass, 1993; Goldstein, 1998; Moss et al., 1993; Domenech-Clar, Nauffal-Manzur; Parpina-Tordera; Compte-Torrero, & Macian-Gisbert, 2003; Lindahl, et al., 2005). Home ventilator users often report good overall QOL or health status, despite high self-reported levels of functional disability (Bach & Wang, 1995; Baydur et al., 2000; Goldstein, 1998; Moss et al., 1993; Kesteren, Velthuis, & van Leyden, 2001). Significantly, perceived health status tends to be better for individuals with thoracic wall deformity, when compared with those who have neuromuscular or obstructive lung disease (Domenech-Clar et al., 2003).

Fair to good QOL, concurrent with markedly diminished functional status, were reported in a pilot study of a small number of home ventilator users with spinal cord trauma (Glass, 1993). Similar to other studies of ventilator-users, participants indicated that their ability to live at home, with family, was of great significance to their self-assessment of wellbeing. In a 1999 follow-up study of individuals with quadriplegia, Hall et al., found quality of life to be higher than expected, with the majority of 82 persons surveyed reporting that they were glad to be alive. There were no significant differences in QOL measures for those participants who utilized ventilator assistance versus those who did not. However, VAI did report a greater frequency of suicidal ideation than both the population norm and ventilator independent quadriplegic participants, particularly during the first four years post injury. About one-third of the participants in both groups reported problems coping emotionally, and when they were asked what changes would improve the quality of their lives, they emphasized financial, transportation and attendant care issues.

QOL reports tend to vary with the type of ventilation used. Increasingly individuals using NIV report better QOL than those with invasive ventilation (Bach & Wang, 1995). In a 1995 review of home NIV, Simonds and Elliott identified low physical functioning scores in individuals living with restrictive respiratory failure. However, physical functioning scores did not correspond with low mental health scores. In fact, individuals reported mental health and vitality scores comparable to those of the population norm. In addition, scores for other QOL domains were comparable with those of individuals living with other chronic illnesses, such as diabetes or heart failure.

In contrast, a study by Markstrom et al. (2002) identified higher levels of wellbeing in invasively ventilated participants with polio-related respiratory disease, than in those who were non-invasively ventilated. The investigators acknowledged that important variables, other than those measured in the questionnaires, may have been overlooked. For example, the requirement for more frequent healthcare follow-up in those with tracheotomy versus NIV may have resulted in participant perception of greater support.

Goldstein, Psek and Gort (1995) administered an open-ended questionnaire to a heterogenous sample of 98 Canadian ventilator users, of whom 28% were independent with self-care, 33% required some assistance and 39% were entirely dependent on caregivers. In contrast to the findings of Markstrom et al. (1995), participants with tracheostomy reported more negative statements regarding the impact of MV, than did those using NIV, and three percent also indicated that they would never have chosen to have a tracheotomy and regretted not trialing NIV earlier in the progression of their respiratory failure. Significantly, only 38% of participants believed that they had made an informed choice regarding the initiation of MV. Those who perceived a lack of informed choice were more likely to have been ventilated on an emergent, rather than an elective basis. Unfortunately, 45% of the study participants began mechanical ventilation on an emergent basis, and this aspect of their experience was not explored in the study. Despite a lack of perceived choice, 87% reported that they were satisfied with MV and 89% reported that they would choose to be mechanically ventilated if they were making the decision at the time of the interview. Fifty-two percent related that they had initially experienced difficulty adjusting to the ventilator. Although there was perceived

adjustment to LTMV, participant concern with activity limitation and the reliance upon others continued across time.

Brooks et al. (2002) followed up on the prior findings of Goldstein et al. (1995) and developed open-ended questions designed to elicit ventilator users perspectives of the impact of ventilation on their lives. Twenty-six non-ambulatory ventilator users, residing in two Canadian cities, were interviewed. Similar to previous findings, the majority of participants rated their health as good and they were positive about their ventilator use. However, “psychological trauma was associated with the introduction of MV for a number of participants” and several individuals related that ventilator support should have been offered earlier in the progression of their respiratory illness. They also believed that they should have been provided with more timely education about mechanical ventilation (Brooks et al., 2002, p.30). This finding is echoed in other studies, including an investigation of ventilator use in individuals living with spinal muscular atrophy (Bach & Wang, 1995) and a phenomenological study of home ventilator users (Lindahl et al., 2005). A participant in the latter qualitative study stated, “If treatment had been started earlier, perhaps some years of suffering might have been avoided” (p. 39).

In another qualitative study of home ventilator users, the experience of home ventilator utilization was interpreted as being both an unburdening as well as a burden (Lindahl et al., 2003). In general, exploration of the experience of technology utilization in chronic illness has recognized that its use paradoxically enhances autonomy, while also imposing significant restrictions, and the paradox is interwoven within the patient’s life trajectory (Lehoux, Saint-Arnaud & Richard, 2004).

Studies of ventilator utilization have also reported dissatisfaction with healthcare, indicating that healthcare providers lack knowledge of the ventilator and the disease process underlying CRF. In addition, some participants report being ignored when making an effort to inform health care providers of their specific disease and the workings of their ventilator. As a result, ventilator users describe feeling both disempowered and unsafe during episodes of re-hospitalization (Brooks et al., 2004).

Generic studies of chronic illness have reported a tendency for healthcare professionals to cling to their role as expert, as they adopt a “pervasive attitude of disbelief” in the patient’s ability to make decisions on his/her own behalf (Charmaz, 1983; Thorne, Nyhlin & Paterson, 2000, p.307). In general, qualitative study of ventilator users and their families have revealed a perception of vulnerability to health care professional views, and studies indicate that HCP attitudes have an impact upon ventilator utilization.

In the United Kingdom, a study of ventilator-dependent children, by Noyes (2000) revealed that parents were aware of some health care provider views that their child was blocking scarce intensive care beds. Parents also sensed that their child was perceived to be a burden to his or her parents and to society in general (p. 776). Adult ventilator users also report that healthcare providers sometimes convey a belief that their quality of life is diminished by the utilization of LTMV (Brooks et al., 2004). This finding is echoed in other studies, including those of ventilator dependent persons living with Duchenne’s muscular dystrophy (DMD).

Healthcare workers consistently underestimated the QOL of individuals living with DMD (Bach, 1991). Gibson (2001) reported that 25% of physicians caring for

individuals with muscular dystrophy had not discussed the option of MV, citing their belief that the patient would have a poor quality of life. Moss et al. (1993) found that ventilator use by persons with amyotrophic lateral sclerosis was highly correlated with their physician's personal attitudes. Other studies note that physician attitudes may delay communication about respiratory failure and ventilatory options without directly impacting ventilator utilization (Ramelli & Hammer, 2005).

Summary

The majority of studies, concerning long term ventilator utilization have reported that users are generally satisfied with LTMV, reporting quality of life/satisfaction scores equal or better than those of individuals living with other chronic health conditions; however, such studies also illuminate concern regarding the period of adjustment and transition to LTMV. Such concern includes, but is not limited to: perception of informed choice; timing of initial ventilatory support; the need for specific education about LTMV and the timing for such education; challenges related to physical and psychological struggle and the adjustment to the ventilator; stigmatization; attitudes of HCP and concern and worry about episodes of re-hospitalization.

Given that nurses play an important role in the patient's initial experiences of MV and subsequent hospitalizations, efforts to enhance understanding of how nurses may best assist individuals with CRF during their transition to LTMV are required. The next section explores the literature concerning the QOL of informal caregivers in general and specifically as related to LTMV.

Caregivers

Studies about LTMV provide evidence that many individuals have successfully resided in the community for years (Brooks et al., 2002, 2004; Lindahl, et al., 2005; Sevick et al., 1996). Several studies have measured aspects of the caregiver experience and perspective; however very few studies have comprehensively explored the QOL of the caregivers of ventilator users. What follows is a review of studies pertaining to aspects of caregiver QOL in general, as well as an examination of the literature relevant to LTMV and the caregiver experience.

The family caregiver has been described as “kin or non-kin individuals” who provide both functional and affective unpaid assistance to a dependent person with whom a long-term or life-long commitment usually exists (Travis & Piercy, 2002, p. 233). A number of factors, including an increasing prevalence of chronic illness, an aging population and changes in the way healthcare is delivered, have resulted in growing numbers of individuals identifying themselves as family caregivers (Travis & Piercy, 2002,). A proliferation of published studies about caregivers has been seen beginning in the 1980s, with early studies examining the caregiver perspectives of individuals caring for persons with Alzheimer’s disease, cancer and chronic illness. More recent studies have also examined caregiver perspectives within the context of early home discharge and the utilization of supportive technologies, including mechanical ventilation.

Not only do informal caregivers facilitate the care of individuals within their home, but they have also been described as trusted companions, surrogate decision makers and patient advocates (Navaie-Waliser et al., 2002). There is general agreement in the literature that caregivers experience alterations in their wellbeing, not just because

they assist with behavioural care, but because they share their life with another who is chronically-ill and this requires change of roles and routines. These changes may lead to feelings of loneliness, powerlessness, loss and guilt, and a life of social isolation, and uncertainty (Covinsky, et al., 1994; Ferrario, Zotti, Ippoliti, & Zotti, 2003; Ohman & Soderberg; Travis & Piercy, 2002).

While home-based care is generally understood to be less costly than hospital-based care, most studies do not take informal caregiver costs, including lost wages and employment opportunities into account (Goldberg & Frownfelter, 1990; Carnevale, Alexander, Davis, Rennick, & Troini, 2006). Informal care providers save the health care system billions of dollars annually; however they may do so at a significant cost to themselves (Hirst, 2005; Schulz & Beach, 1999). In a prospective, population-based cohort study of 392 caregivers aged 66 to 96 years, Schulz, and Beach (1999) identified that being a caregiver, experiencing mental or emotional strain, is an independent risk factor for mortality.

Hirst (2005) examined psychological distress around transitions into and out of caregiving and found both an independent association between caregiving and psychological distress, and a significant relationship between increasing time demands of the role and increased distress scores. The author reported that findings served to “begin to validate caregiving as an underlying social determinant in the creation of health inequalities” (p.705).

The study of factors influencing health promoting activities of mothers caring for ventilator-assisted children found that the functional status of the child and positive family coping were positively correlated with the mother’s participation in health

promotion activities (Kuster, Badr, Chang, Wuerker, & Benjamin, 2004). However, when the child's functional status declined, the mother's health promotion activities were increasingly ignored.

Scores of studies concerning caregiving for individuals with Alzheimer's disease have been undertaken. Coen (1997) reviewed QOL for caregivers of persons with Alzheimer's disease and concluded that caregiver QOL and level of burden should be taken into account when considering proxy judgments of patient QOL. Significantly, they found behavioural disturbance to be a more significant determinant of caregiver strain and depression than physical disability. Similarly, in a recent study of survivors of acute respiratory distress syndrome, caregiver wellbeing and psychological status were adversely affected by care recipient depressive symptoms. However, survivor functional status, as measured by the six minute walk test, did not correlate with caregiver wellbeing or psychological distress (Cameron, Herridge, Tansey, McAndrews, & Cheung, 2006). These studies indicate that cognitive and/or emotional impairment in the care recipient may represent a more significant challenge to caregiver wellbeing than functional disability. While VAI often experience significant functional disability, they do not usually experience concomitant cognitive impairment.

Some studies have revealed higher depression scores and lower QOL scores for caregivers than for those of the individual living with the chronic illness (Kornblith, Herr, Ofman, Scher, & Holland, 1994; Weitzenkamp, Gerhart, Charlifue, Whiteneck, & Savic, 1997). A prospective cohort study of caregivers of persons who had been mechanically ventilated for greater than 48 hours revealed that a high proportion of patients continued to require caregiver support two months following their liberation from MV and 34% of

caregivers were at risk for clinical depression (Chelluri, Im, Belle, Schulz, Rotondi, Donahoe et al., 2004). Similar findings were evident in a study of 135 caregivers of persons who had required a long period of MV in the ICU. Their depression scores were higher than those caring for individuals living with other chronic illnesses, and scores were highest in caregivers whose spouse was institutionalized (Douglas & Daly, 2003). However, in a study of caregivers of stroke survivors, location of the patient was not found to be a factor in caregiver strain scores (Bugge, Alexander & Hagen, 1999).

Ferrario, Zotti, Zaccaria and Donner (2001) measured caregiver strain in 63 participants caring for individuals with chronic tracheostomy. Measures were recorded at the time of initial hospital discharge, and one year following hospitalization. The authors report that the care of an individual with a tracheostomy resulted in a substantial amount of caregiver strain. Similarly, caregivers of individuals requiring invasive LTMV, via tracheostomy, have reported more negative views and higher stress levels when compared to caregivers of individuals utilizing NIV. Likewise, in a study of caregivers of children with tracheostomy and gastrostomy, high levels of strain related to tracheostomy care were identified and interviews revealed an overwhelming worry about the potential loss of the airway (Montagnino & Mauricio, 2004). Issues pertaining to suctioning, stigma, and the need to have and maintain more equipment have been identified as factors that increase caregiver burden (Brookes et al, 2002; Goldstein et al., 1995).

Issues concerning mechanical ventilation and palliative care for individuals living with amyotrophic lateral sclerosis (ALS), a progressive neurodegenerative motor neuron disease for which there is no known cure, have been quite well explored using both qualitative and quantitative research design and methods. Caregiver concerns have also

been explored (Ganzini, Johnston, & Silveira, 2002; Miller et al., 1999). In one study of both individuals with ALS and their family caregivers, ninety percent of participants indicated that they were glad to have chosen home MV; however, family caregivers also reported major burdens and 50% of them indicated that they would not choose MV for themselves. More female than male caregivers reported that they would choose not to be ventilated (Moss et al., 1993). The authors concluded that MV is effective for the minority of persons with ALS who choose it, but the burden on the caregiver is great. Further exploration of caregiver perspectives would help to illuminate the perspectives of the 50% of persons who stated that they would not choose to ventilate. In another, more recent, study of caregivers of persons with ALS, both the patient and caregiver reported higher levels of strain in each other, than for themselves, suggesting challenges to proxy judgments of QOL (Adelman et al., 2004).

Beneficial aspects of the caregiving experience have also been reported. Berg-Weger, Rubio & Tebb (2001) performed a secondary analysis of qualitative data from their study of 75 persons caring for family with chronic illness. Positive aspects of the caregiving experience were identified, including enhanced coping and spiritual connection. Other caregivers report greater wellbeing while caring for their family member at home, when compared with the time their family member was hospitalized (Berg-Weger et al, 2001). Rees, O'Boyle and MacDonagh (2001) explored the experience of caregiving, and identify that family are perceived to be visitors when family members are hospitalized, but at home they become caregivers and care managers, which may positively impact caregiver self-esteem. Families of ventilated individuals

have reported experiencing a sense of satisfaction and strength when providing their care at home (Smith, Mayer, Perkins, Gerald, & Pingleton, 1994).

Many studies, including those exploring the emotional aspects of caregiving for a mechanically ventilated family member, report high levels of strain and burden; however, family caregivers also report that home placement is not a negative experience (Brooks et al., 2002; Lindahl, 2005). While few studies definitively identify the cause of caregiver strain, scores have consistently reported caregiver strain to be positively associated with the number of hours and intensity of caregiving (Sevick et al., 1996; Sevick et al., 1994). Factors that increase the intensity of caregiving include the frequency and number of symptoms experienced by the care recipient, the complexity of technological care and the frequency of re-hospitalization (Kochinda, as cited in Winkler, Ross, Piamjariyakul, & Gajewski, 2006). Social support has also been identified as a significant factor in the wellbeing of both the care recipient and the caregiver. Studies of mothers who care for children with chronic physical conditions have indicated that mothers' strain can be ameliorated, to some extent, by hopefulness, but hope was not found to be a mediating factor in depression related to a lack of social support (Horton & Wallander, 2001).

The literature also identifies evidence of gender inequities regarding the caregiving experience; with a greater number of women identifying themselves as caregivers (Jecker, 2002). In a study of continuous positive airway pressure treatment, female spouses were three times more likely to attend teaching sessions than were their male counterparts (Smith et al., 1998). In studies of caregiving for dependent children, a greater loss of income, and higher level of caregiver strain is reported in mothers than fathers. (Noyes, Hartmann, Samuels & Southall, 1999; Kuster, Badr, Chang, Wuerker &

Benjamin, 2004). Similarly, generic studies of caregiving and chronic illness report that women experience higher levels of burden, strain and depression than do their male caregiving counterparts (Sawatsky & Fowler-Kerry, 2003; Hirst, 2005). This has been found to be true for caregivers of ventilated individuals as well (van Kesteren, Velthuis, & van Leyden, 2001).

Many studies examining caregiver experiences have identified the need for more comprehensive teaching programs prior to discharge (Kopacz & Moriarty-Wright, 1984; Smith et al., 1994; Thompson, & Richmond, 1990). Literature on the discharge process for home ventilator users, suggests the need for more optimal discharge programs, as the process is complex and requires the coordination of multiple disciplines and resources. Education and training of caregivers necessitates the dedication of individuals who are knowledgeable regarding teaching and learning principles and are able to demonstrate knowledge, patience and understanding (Glass, Grap, & Battle, 1999). Studies of caregivers looking after ventilated and/or tracheostomy patients have revealed deficiencies in the discharge process, including inadequate communication between agencies, and a lack of attention to the “emotional component in learning new procedures” (Margolan, Fraser, & Lenton, 2004, p.258).

A long-term follow-up study of individuals with high cervical spine trauma and quadriplegia noted that the ventilated individual became responsible for teaching others about their care. The authors assert that outpatient educational support should be accessible to VAI on an ongoing basis (Hall et al., 1999).

Summary

Overall, review of the literature reveals that increasing numbers of individuals are caring for complex, chronically ill persons in the home, while others significantly augment the formal care that is provided within healthcare institutions; however, few studies provide an in-depth exploration of the caregiver perspectives and the meaning of living the caregiving experience. This is particularly true for caregivers of individuals who utilize LTMV. Informal care providers require particular attention and understanding as they are essential to the success of home ventilation and are integral to the wellbeing of the patient; however, their own health should be of concern as well. In order for nurses to provide optimal patient care, the family needs to be as the “unit facing illness” rather than simply a refuge or advocate for the patient (Leavitt, 1989, as cited in Rennick, 1995, p.258).

Transition

Transition is a concept that is central to the discipline of nursing as nurses often encounter clients during transitional periods in their lives (Schumacher & Meleis, 1994). Transition is a dynamic phenomenon, characterized by process, rather than any single event and defined as: “The passage or movement from one state, condition or place to another” (Chick & Meleis, 1986, p. 237). Exploration of the literature concerning transition reveals a diversity of transitional situations deemed to be of interest to the nursing discipline, and a number of studies, literature reviews, and conceptual and meta-analyses have explored transition as it pertains to the health and illness trajectory.

As survival for children and youth with chronic illness has increased, so too have the number of articles exploring transition as it relates to the challenge of adjustment to

adult care for adolescences with chronic illness (Anderson, Vogel, Betz, & Willis, 2004; Blum, 2002; Boyle, Farukhi & Nosky, 2001; Flume, Taylor, Anderson, Gray, & Turner, 2004; Madge & Bryon, 2002; Reiss & Gibson, 2002; Scal, 2002; Scal, Evans, Blozis, Okinow & Blum, 1999; Stabile et al., 2005; Viner, 2000). Other articles specifically investigate developmental or life stage transitions (Burton, Zdaniuk, Schulz, Jackson & Hirsch, 2003; Davies, 2005; Nilsson, Sarvimaki & Ekman, 2000); while still others review phenomena specific to chronic illness and disease (Kralik, 2002; Lowes, Gregory, & Lyne, 2005; Neil & Barrell, 1998; Shaul, 1997; Wilkins & Woodgate, 2006; Woodgate & Degner, 2004); or explore illness trajectory and the movement from one point of care to another, within the health system (Chaboyer, James, & Kendall, 2005; Daff et al., 2006; Naylor, Bowles & Brooten, 2000). The study of transition in nursing has resulted in emerging mid-range theoretical development (Schumacher & Meleis, 1994; Meleis, Sawyer, Im, Hilfinger, & Schumacher, 2000).

Transition theory is particularly relevant to the study of individuals and families living with chronic illness, as it provides a comprehensive framework for assessment of a number of variables that potentially affect a complex and highly individualized process. The process that precedes the stable adjustment to LTMV is characterized by many changes and adaptations that occur over an individual timeframe; hence the conceptualization of the period as one of transition. Individuals who transition to LTMV experience a number of observable events or adjustments including: the symptom experience of respiratory failure, adjustment to being mechanically ventilated, subsequent tracheotomy (for individuals on invasive ventilation), a period of learning to breathe on a model of ventilator designed for long-term maintenance, and planning for and going

home or to long-term care facility. While one could investigate any one of the specific, aforementioned changes or events, the inquiry underlying this study considers the transition, or the whole of the experience.

A qualitative study by Kralik (2002) explored 81 women's experiences of living with multiple sclerosis, and found that transition was non-linear and involved movement from extraordinariness to ordinariness. Movement to ordinariness required the restructuring of one's life with illness. The author suggests that nurses who understand illness as transitions are able to work within a framework that assists them to move beyond a bio-medically oriented practice, to a more holistically oriented one.

Neil and Barrell (1998) also studied the concept of transition as it arose in the life of persons living with chronic wounds. Their findings were similar to Kralik's (2002) in that the participants reported a disrupted reality that was accompanied by uncertainty and ultimately required a restructuring of reality. The authors also suggest that nurses need to become more aware of the transition process, as they may then be able to facilitate the course through which individuals restructure reality. Lowes et al. (2005) studied the experience of being a parent of a child newly diagnosed with diabetes. They framed their understanding of the experience as a psychosocial transition and related that this assisted them in understanding the grieving and adaptation process that parents underwent concurrent with the process of learning about the disease and its management.

A recent phenomenological study by Johnson (2004) explored the experience of long-term ventilated patients in the ICU. Findings indicate that, "patients want more control over their environment and instigate ways to facilitate this" (p.190). The author viewed participants as struggling to re-engage and reclaim the everyday world, which is a

similar concept to struggling for ordinariness and reclaiming reality. Common to most studies exploring health and illness through transition are the implications for nursing practice.

Understanding illness experience as a time of transition, and gaining an appreciation for the nature and complexity of the transition process, may facilitate the nurse's ability to view illness as a process involving the whole of the person; the challenge of doing so may be in recognizing that a greater engagement in psychosocial aspects of care is required.

It is significant that transition experiences are often described as involving mental processes and the individual meanings that are attributed to events as they transpire (Schumacher, & Meleis, 1994). Transition experiences are, therefore, likely to be best understood through exploration and illumination of individual perspectives. Significantly, one study of transition in illness reported, "Nurses are best suited to guide people with chronic illness through transitions, but they need to know how and when to intervene" (Shaul, 1997, p.203). Study of the lived experience of transition to LTMV provides nurses and others with such knowledge.

Conclusion

The literature review highlighted much of what is known about LTMV to date. The incidence and prevalence of chronic respiratory failure is on the rise, and ventilator technologies have improved to the extent that growing numbers of individuals are living at home on mechanical ventilators. The majority of studies exploring ventilator user satisfaction and QOL have been carried out with community/home dwelling individuals.

While tracheostomy and invasive ventilation continue to be necessary for those with airway management issues and intractable respiratory failure, fewer individuals are invasively ventilated today, which may result in decreased incidence of nosocomial pneumonia, and decreased hospital length of stay. The overall utilization of non-invasive ventilation has increased significantly and initial studies indicate that, when compared with invasive ventilation, a greater number of persons on NIV are satisfied with its use.

Quality of life for most ventilator users is reported to be at least satisfactory, with many individuals reporting very good quality of life. Functional impairment is high for ventilator users, particularly those with neuromuscular disease; however, the degree of functional impairment is not highly correlated with QOL scores. Rather, the presence of depressive symptoms and/or psychological distress has been identified as a more significant determinant of poor QOL. Ventilator users uniformly report concerns related to their lack of independence and issues with transportation and the ability to access satisfactory assistants.

To date, there are insufficient studies exploring the family caregiving experience with ventilated individuals living at home or in long term care facilities. Similar to the findings in the generic caregiving literature, studies of caregivers of VAI report a paradox of burden, concurrent with satisfaction in the choice to be a caregiver. Mediating factors such as social support, respite, and access to ongoing education have been reported to enhance the caregiver's role. A number of studies identify caregiver distress as being most positively correlated with: 1) increased duration and intensity of caregiving responsibility, and 2) the presence of depressive symptoms or cognitive loss in the care recipient. Many caregivers suffer both physical and psychological morbidity in relation to

their role and responsibilities. Of note are studies indicating that caregiver stress may prevail or increase when the care recipient is institutionalized.

The concept and theory of transition has informed many studies, particularly those concerned with chronic illness. Theory has served to describe a process of restructuring reality that is a common concern for many individuals and families living with chronic illness. Health professional knowledge and understanding of the theoretical aspects of transition has served to promote client-centered interventions and family support.

Several pertinent gaps in the literature were identified. First, a preponderance of study regarding LTMV has focussed on home ventilation, and few studies explore the perspectives of VAI who reside in long term care facilities. Secondly, no studies have sought to specifically capture the perspectives of transition in individuals with CRF, requiring LTMV. Third, few in-depth studies of caregivers of long term mechanically ventilated individuals have been undertaken, as a result little is known about the paradox of burden and satisfaction concomitantly reported by this population. Lastly, little is known about caregiver perspectives of transition during their family members' protracted hospitalization and adjustment to technology.

Increasingly healthcare systems are required to respond to significant societal trends. One such trend is the movement toward the integration of informal caregivers into the healthcare system. More information about the experiences and needs of caregivers is required, particularly with respect to distinct populations for whom study has, thus far, been limited.

Previous research studies (Goldstein, et al., 1995; Brooks, et al., 2002 & Lindahl et al. 2005) have particularly pointed the way for this study in that they provided data and

narrative about the experience of being ventilated. Findings call attention to the initial transition as a time of particular psychological and physical challenge. Health care systems and providers are best able to assist individuals during these times of challenge, when they are informed about the dimensions of the experience. This literature review provided support for an in-depth exploration of transition experiences of ventilator users and their caregivers to LTMV with attention to illuminating the meaning of their experiences through narrative interpretation, guided by the principles of phenomenology.

CHAPTER THREE: METHODOLOGY

Introduction

In chapter three, the overall methodology of this research study and the philosophical underpinnings of the particular approach used for this project are described. Methodology refers to the philosophical framework that is used to guide a study from its inception through to the analysis of findings, while the method refers to the procedures and technique that are employed to plan and perform the research (van Manen, 1990). What follows is a discussion of the philosophical underpinnings of phenomenological inquiry and the specific approach chosen for this study. In addition, the research method is outlined, including the design, population and participant selection process, setting, data collection methods, and approach to data analysis. Lastly, ethical considerations, potential study limitations and the means of establishing methodological rigour, or trustworthiness, are discussed.

A qualitative research approach was selected for this study because little is known about the transition experiences as lived by individuals requiring LTMV and their caregivers. Creswell (1998) identifies qualitative design as appropriate in situations where a topic needs to be explored, where variables are not easily identified, and where one needs to present a detailed view of the topic.

This study aimed to reveal the meaning people attribute to their experience of transition to LTMV. This is a question concerning human experience. It is about experiencing a phenomenon as a person in a specific situation, at a specific time. The methodological approach ought to be capable of answering the question being asked. Accordingly the methodology chosen for this qualitative study was ontological-

hermeneutics, a phenomenological approach informed by the ideas of the German philosopher, Martin Heidegger (1889-1976). Phenomenology is well suited to the investigation of human experience, as its focus is on the whole human experience and the meaning that is attributed by people who have lived through the experience.

A methodological approach is situated within a paradigm, or a worldview concerning how truth and knowledge are perceived. Guba and Lincoln (1994) suggest that four research paradigms exist as follows: positivism, post-positivism, critical theory, and constructivism/interpretivism. This study was situated within the interpretivist/constructivist paradigm. Crotty (1998) has described this paradigm as a human science in which one is concerned with understanding or *Verstehen*, rather than causality or explanation. There is a strong emphasis upon relativism, or a stance emphasizing the existence of multiple constructed realities.

A phenomenologist seeks to co-create a construction of the phenomenon through subjective interpretation of the words of the person who has experienced the phenomenon (van Manen, 1990). This approach contrasts with methodologies undertaken within a positivist or post-positivist paradigm, as the researcher's intention is not to stand entirely separate and objective from the research process or participant. However, in doing so, the phenomenologist is not "merely undertaking a speculative inquiry in the sense of unworldly reflection" (Munhall, 1994, p.61).

Hermeneutic phenomenological research

Hermeneutic phenomenology is interpretive and focuses on the study of phenomena as they are experienced or perceived (Munhall, 1994). Through interpretation, the essential elements or essences of human experience may be

understood. In this way, a deeper understanding of lived experience may be generated. The research approach of phenomenology has been used by a number of disciplines including anthropology, sociology, psychology and nursing.

Van manen, (1990) has described phenomenology as a research methodology that seeks to gain access to the outer world (life world) from human experience (consciousness), through the processes of reflection and intuiting, which ultimately results in a thematic understanding of the meaning of experiences. Two main phenomenological approaches have been described, Husserlian and Heideggerian. While this study will use a Heideggerian approach, both are described.

The Husserlian tradition is based upon the work of the German mathematician and philosopher, Edmund Husserl (1859-1938), who has been recognized as being central to the phenomenological movement (Cohen, 1987). Human consciousness was situated at the heart of his philosophy. He sought to illuminate the content and method of the mind (Koch, 1995). His work was grounded in tenets of positivism as he strived for rigour in his method, believing that objectivity was an admirable goal for the researcher, and that it was achievable through engagement in a process of detachment and the bracketing of all biases and assumptions (Annells, 1996). His interest concerned how humans know what they know, the study of the essence of lived experience. His method required systematic description with rigorous attention to bracketing of prior knowledge, understandings and biases.

Heideggerian phenomenology challenges some of the assumptions underpinning Husserl's perspective. In particular, the way in which phenomenology informs meaningful inquiry is both modified and expanded (Lopez & Willis, 2004). Rather than

focus on the epistemological nature of inquiry, Heidegger primarily concerned himself with ontological inquiry, or the meaning of human experience. This divergence in inquiry resulted in a second tradition of phenomenological inquiry known as hermeneutics.

The word, hermeneutic, is derived from the name Hermes, a Greek god who was responsible for interpreting messages from the gods (Thompson, 1990). Hermeneutics essentially concerns the process of interpretation. Spiegelberg (1976) identified hermeneutics, or hermeneutic interpretation, as a process and method for bringing out and making manifest what is normally hidden in human experience and human relations (As cited in Lopez & Willis, 1990). Meaning is not always apparent or accessible in conscious knowing; rather it is embedded in experience. Therefore, it is the capturing of experience, through narrative and subsequent interpretation that ultimately illuminates meaning. The experience and the context in which it occurred are not separate, but are viewed as a whole. Heidegger used the term *being-in-the-world* to capture his view that humans cannot abstract themselves from the world (Lopez & Willis, 1990, p.729). This philosophical principle also influenced Heidegger's views of the role of the researcher.

He did not espouse a rigorous process of bracketing as Husserl had; rather he advised researchers to make their prior knowledge, preconceptions, and biases explicit and to explain if, when, and how they affect the inquiry and interpretation process (Annells, 1996). In this regard, van Manen (1990) asserts that the phenomenologist needs to be cognitively and deliberately aware of holding prior knowledge and assumption at bay, continually questioning those assumptions and "turn(ing) the knowledge against itself" (1990, p.47). Munhall (1994) describes bracketing from the phenomenologist viewpoint as a "knowing from the very soul, that for others, it (the phenomenon) might

be different and then being able to allow others their perceptions is the way to hearing in a phenomenological way” (p.61).

Theoretical anchoring is a term used to describe how literature review and analysis serve to focus phenomenological research inquiry (van Manen, 1990). As with prior knowledge and assumption, theoretical anchoring needs to be explicit and the researcher should provide evidence that its use did not bias analysis (Lopez & Willis, 1995). For example, in this study an exploration of transition theory served to focus the inquiry upon the experience as a process that occurred over time; however, it is possible that narrative interpretation would discount this view and instead support only the notion that discreet and unrelated events occurred. In hermeneutic interpretation, more than one interpretation of the narrative is possible; however interpretive findings must be plausible, logical and reflect the realities of the study participants experience (Annells, 1996).

Limitations of Ontological-Hermeneutics

There are important limitations to all research methodologies, and the researcher should recognize and acknowledge the specific limitations associated with their choice of methodology. Phenomenology does not attempt to predict, generalize or generate theories. Instead, it aims to increase the understanding of certain phenomena and the meaning attributed to them (van Manen, 1990). This is of value in as much as nurses are concerned with human experience and a better understanding of patient and family perspectives may serve to enlighten nursing practice.

Appropriateness of Hermeneutic Phenomenology for this Study

Hermeneutic phenomenology was an appropriate approach for this study as the researcher has prior experience with, and knowledge of the phenomenon; however, that prior experience is acknowledged to be narrow in focus. Munhall (1994) argues that it is necessary for nurses to understand the lived experience of their clients, in different settings, to facilitate the planning of optimal care. The intent of this research inquiry was to gain a deeper understanding, an *emic* or insider view of the meaning of the experience of transition to LTMV for individuals, and their family caregivers.

Method

The following section describes the research design that was implemented in order to acquire the participant sample and information rich data. In addition, the research setting, data collection methods, approach to data analysis, ethical considerations and issues of methodological rigour/trustworthiness are detailed.

Research Design

As discussed in the previous section, the methodological approach to this study is qualitative phenomenology, and is specifically founded upon Heideggerian philosophy, which searches for truth in the meaning in *Being*, through the illumination of lived experience. "Phenomenological research borrows other people's experiences and their reflections on their experiences in order to better be able to come to an understanding of the deeper meaning or significance of an aspect of human experience in the context of the whole of human experience" (van Manen, 1990, p.63). People assign meaning to their experiences; however, those meanings are not always clear, but may become so when explored through introspection.

This study sought to illuminate the meaning of living the experience of transition to LTMV from the perspective of VAIs and family caregivers. The research method should be guided by the research question (Creswell, 1998, p17). The methods outlined by van Manen (1990) were used to guide the interpretive procedures of this phenomenological study.

Although there are a number of established methods for phenomenological research, many are based on the tradition underlying the discipline of psychology (Collaizi, as cited in Creswell, 1998; Giorgi, 1975; van Kaam, 1959). Van Manen's method was chosen principally because it reflects the ontological, interpretative assumptions that underlie Heideggerian phenomenology. Van Manen's methods embrace the notion that the researcher is intimately involved with the process of interpretation; however, prior knowledge, assumption, and biases concerning the phenomenon are made explicit and are critically reflected upon during every stage of the research project.

Van Manen's method has also demonstrated utility and flexibility in that it has been used to guide numerous phenomenological studies in a variety of disciplines, including nursing (Blau et al., 2002; Beal & Quinn, 2002; Caliandro & Hughes, 2002; Johnson, 2004; Sturge-Jacobs, 2002). Van Manen's approach identifies six methodological themes, which structure the research process (see table 3.1). In this study, the research process unfolded with periods of both simultaneous and intermittent attention to each of the activities:

Table 3.1

*Van Manen's human science method for hermeneutic phenomenology (1990)**The Research Process*

van Manen's (1990) Methodological Themes	Research Activities for this Study
Turning to a phenomenon which seriously interests and commits us to the world	Literature review, proposal, recruitment of participants
Investigating experience as we live it rather than as we conceptualize it	In-depth interviews
Reflecting on the essential themes which characterize the phenomenon	Analysis
Describing the phenomenon through the art of writing and rewriting	Interpretation of emerging themes, writing and re-writing themes
Maintaining a strong and oriented pedagogical (nursing) relation to the phenomenon	Refer to the research question and purpose, nursing experience and literature
Balancing the research context by considering parts and the whole	Movement from themes to the entire transcripts of individual interviews

Sample selection criteria

Participants in phenomenological inquiry are persons who have experienced the phenomenon of interest and are able to articulate the meaning of their experience (Creswell, 1998). The investigator seeks in-depth description of the phenomena of interest from information-rich cases (Patton, 2001). Ventilated individuals met the criteria for this study if they:

- (1) were male or female, aged 18 years or over, and were able to speak, read and write English;
- (2) required mechanical ventilation, either invasive or non-invasive, for the treatment of CRF, for at least six hours/24 hour period;

- (3) had experienced transition to LTMV at least six months prior to the commencement of study, and were able to recall and articulate their experiences; and
- (4) were willing to participate in the study by giving written consent following an explanation of the study, and the requirements for participation.

Family caregivers of ventilator users met the criteria if they:

- (1) were individuals (not necessarily related to the VAI), who provided unpaid care for the ventilator user during the period of transition to mechanical ventilation; and
- (2) were willing to participate in the study by giving written consent following an explanation of the study, and the requirements for participation

Participant access

Human ethics approval was received on May 4th, 2006 from the University of Manitoba Education and Nursing Research Ethics Board (ENREB). Approval for participant access was received from two health care facilities in May and June, 2006 (see Appendix A).

Sample recruitment

Invitations to participate in the study were provided to ventilator users who attended a Respiratory Outpatient Clinic (RSOPD) at a midwestern Canadian tertiary care facility. The clinic serves the majority of home ventilator users in a Midwestern Canadian province, as well as those residing in the northern area of a neighbouring province. Invitations were also sent to ventilator users residing on a respiratory unit at a midwestern

Canadian long-term care facility and informal caregivers, who were identified by ventilator user participants.

Recruitment transpired with the assistance of two nurse clinicians in the RSOPD, and two allied health care providers at the LTC facility (see Appendices B & C). After ensuring that the nurses and allied health care providers understood the eligibility criteria (see Appendix D), they were provided with a brief script about the study so that it could be read to potential ventilator user participants, thus providing uniformity in the presentation of initial study information (see Appendix E). The letter included information about the investigator, her student status and affiliation, and the general purpose and nature of the study. The clinic nurses mailed letters to the homes of ventilated individuals, who were not likely to attend clinic during the study recruitment period (see Appendix F). All letters included contact information and a self-addressed, stamped envelope.

All community dwelling participants contacted the researcher directly by telephone or e-mail, while those who resided in LTC released their names to the person reading the letter, and I contacted them in person. I provided study information to all potential participants using a script (see Appendix G). Potential participants who met all of the eligibility criteria, and were interested in participating in the study, met with me. Those who agreed to participate in the study engaged in a formal consent process, at which time I reinforced their opportunity to withdraw at any point, refuse to answer any question or end the interview at any time (see Appendix H).

After ventilator user consent was obtained, those who identified having an informal caregiver were asked to provide caregivers with a letter asking whether they

wished to receive information about the study (see Appendix I). Interested caregivers contacted me directly and I met them in their home or at the LTC. Caregivers were read a script about the study and those who were willing to participate also engaged in the formal consent process described earlier (see Appendix J & K).

All community dwelling individuals were advised that clinic staff would not be informed of either their agreement or refusal to participate in the study. Participants who resided in LTC were informed that I would not be discussing their interviews with the unit staff.

Sample size

Eleven ventilated individuals and eight family caregivers were selected over the course of four months. One family caregiver had numerous obligations and was unable to meet for an interview during the period of study, therefore the final sample size was 18, of which seven were family caregivers and 11 were ventilator users.

No statistical formulas for determining sample size exist for qualitative research (Coyne, 1997; Sandelowski, 1995). Final sample size was determined emergently, which meant that the researcher and the thesis supervisor critically reviewed data and evaluated the extent to which the research questions were being comprehensively answered (Coyne, 1997; Patton, 2002). This process is similar to that described as saturation by Glaser and Strauss (1967). The first ventilated and caregiver participants were utilized to pilot the interview procedures and their data was included in the findings, as procedures did not require significant change.

Data Collection Methods

Data were collected using a demographic form (see Appendices L & M) that was developed by the researcher; a short form 12 version two (SF-12) health survey (Ware, Kosinski, & Keller, 1996), field note recordings, and in-depth semi-structured interviews that were guided by open-ended interview questions (see Appendices N, O, & P).

Demographic form

After engaging in informal conversation, and prior to commencing the audio-tape recording of each interview, participants were asked to complete a demographic and health questionnaire. The forms were utilized in order to elicit information that would provide description of each participant and the population in this study (ventilator users and family caregivers). The demographic form contained questions regarding demographics (e.g., age, employment), as well as information about ventilator use and the background of the ventilator user and his or her caregiver.

The SF-12 health survey

The SF-12 health survey (Ware, Kosinski & Keller, 1996) is a shorter version of the short form-36 (SF-36) (Ware & Sherbourne, 1992). The short form SF-36 is a generic health survey tool derived from a two-year Medical Outcomes Study (n=22,462), and developed in the United States (Tarlov et al., 1989). It has been widely employed throughout the world to measure self-reported health status. Its psychometric properties have been well validated in many populations, and its norm based scoring method allows for comparison of self reported health status across groups living with a variety of chronic illnesses. It has been used to measure health status in many populations,

including in those living with chronic respiratory disease (Domenech-Clar et al., 2003; Euteneuer et al., 2005).

The SF-12 was developed in an effort to decrease responder burden by decreasing the length of time required to complete the form. The authors suggest that completing the SF-12 survey requires approximately two minutes time (Ware & Sherbourne, 1992). Psychometric methods were employed by the original developer to reduce the number of health dimensions assessed, without substantial loss of information. The SF-12 has also been used in studies of persons with chronic (mostly obstructive), respiratory disease, and has been shown to have high concordance with the SF-36 survey (Jenkinson et al., 1997; Johnson & Coons, 1998; King, Horowitz, Kassam, Yonas, & Roberts, 2005; Miravittles et al., 2002; Scherer, Spengler, Owassapian, Imhoff & Boutellier, 2000).

The scoring of the survey provides values for eight domains of function including: physical functioning, role limitations due to physical health problems, bodily pain, general health, vitality (energy/fatigue), social functioning, role limitations due to emotional problems, and mental health (psychological distress and wellbeing) (Ware et al., 1996). The scores are aggregated to generate both a physical component summary scale (PCS) and mental component summary (MCS) scale. The authors transform the scales so that the scores of the general population (norm based) have a mean score of 50 and standard deviation of 10. As with the SF-36, participant scores are transformed via the author's formula, facilitating comparison with general population norms and the norms for populations living with a variety of chronic illnesses. A score of 0 represents the lowest possible health score and a score of 100 represents the highest possible health score (Ware, Kosinski, Turner-Bowker & Gandek, 2005).

The health survey tool was piloted in this study in order to compare ventilator user perception of health with that of their caregiver counterparts. Literature review had identified that caregivers sometimes report lower health status than their care recipient counterpart. The health survey tool also facilitated the comparison of participant scores with population norms and those of individuals living with other chronic illnesses. The tool was chosen because of its brevity and its widely published use in studies of individuals living with chronic illness.

It should be noted that the goal of using the SF-12 health survey was not to achieve results that were statistically significant, but to provide background information about the participants' health status.. The overarching purpose of this study was to provide an in-depth description of the lived experience of transition to LTMV; therefore the sample size was purposefully small. To diminish the possibility of SF-12 scores influencing narrative interpretation, the forms were not scored until the narrative data analysis was concluded.

In-depth, semi-structured interviews

Ten participants chose to be interviewed in their home, apartment or room in a LTC facility. One participant chose to be interviewed in a private location at a post-secondary institution. Interviews were 15–120 minutes in duration. One participant was interviewed five times for 15-20 minutes; two were interviewed three times for 40 – 90 minutes; and one was interviewed twice for 30-80 minutes. The remaining 14 participants were interviewed once for 50-120 minutes.

Nine of the 11 ventilated participants utilized mechanical ventilation during the interview. No participant complained of fatigue or respiratory distress, and all but one

participant, spoke audibly and clearly. One VAI was no longer able to articulate due to the progression of neurodegenerative disease, therefore a word board was used and the spouse was usually present to assist. Interviews with that individual were shorter (15-20 minutes) than the interviews with the other participants. Time was also spent being with the individual, sharing through pictures and other memorabilia that helped to tell the story of a life and the transition to LTMV.

A second participant, who was not mechanically ventilated during the interview, displayed increased work of breathing; however, when I noted this, the participant chose to continue with the interview, stating that the degree of respiratory effort was normal. One participant required suctioning prior to the interview, but was able to articulate well throughout.

Four of the seven VAI/caregiver dyads chose to be together, off and on, during their respective interviews, which may have had an effect on the information that was disclosed/not disclosed. No paid attendant was present in the room, during any of the interviews.

In terms of the structure for the in-depth interview, guiding questions and probes were used in order to assist in exploring similar inquiry with all participants, while also enhancing depth of inquiry. The guide also allowed for emergent variation to occur in response to each individual. (Morse, Barrett, Mayan, Olson, & Spiers, 2002). In addition, because preliminary analysis began during the first interview and continued concurrently with ongoing interviews over a four month period, questions asked during my dialogue with the text served to guide ongoing participant discussion. This provided an

opportunity to discuss more deeply, the meanings that participants attribute to their experience of the phenomenon (Creswell, 1998, Patton, 2001).

During and following each interview, I checked my understanding and interpretation of what had been said with the participant. At the close of each interview, participants were asked whether there was anything else they wished to share. Participants often chose to reinforce how they believed health care providers could improve their understanding of LTMV and their care of ventilated individuals and their families.

Interviews were all audio-tape recorded, and subsequently transcribed verbatim. Field notes were also recorded following each interview in order to provide a description of the interview experience, setting, non-verbal communication and any technical or logistical issues that may have occurred.

I made every effort to ensure that the audio-tape recorder functioned well; however, when I began listening to one of the participant interviews in my car following an interview, I discovered that one side of a tape was blank. Fortunately, the participant agreed to meet with me again. When I had discovered the problem, I immediately wrote out all of my recollections of the missed portion of the interview so that I could revisit those thoughts and ideas during the follow-up interview.

Data analysis

Due to my past professional experience caring for ventilated patients, I brought prior understanding of the phenomenon of interest to the research project. I endeavoured to adopt a Hermeneutic phenomenological perspective, which considers the observer to be inseparable from the world (Heidegger, 1927/1962), thus I recognized that I would be

entering the participant's world, just as they would be entering mine. Being conscious of this reality is vital, as one then implements strategies to forestall subjectivity and opinion from leeching into the interpretation process.

In addition to the description of my prior work and assumptions outlined in chapter one, a comprehensive description of my own experience with the phenomenon of transition to LTMV was documented in a journal. I reflected upon my pre-understandings and assumptions throughout the course of data collection and analysis in order to maintain a consciousness of prior knowledge, in an effort to diminish the likelihood of its influence on the interpretation of current data. Reflective journaling is a strategy recommended to ensure transparency, by providing an audit trail so that both ethical and methodological decisions can be questioned. (Maggs-Rapport, 2001 & Meyrick, 2006; Munhall, 1994).

In phenomenological methodology, both data collection and analysis occur concurrently, in order to assure maximal responsiveness of the investigator to the analysis process. Participant audiotapes were listened to following each interview, prior to transcription, in order to review the interview experience, ensure clarity and begin a data immersion process (Morse et al., 2002). Each interview was recorded as a distinct file, absent any identifying information, in a Word 2000 Program and is available for audit. Following transcription, audiotapes were reviewed in order to ensure accuracy of transcription and to continue to facilitate the immersion process. Tapes and transcripts were then reviewed many times over the course of several months, in order to identify significant statements, and meaning units or themes (van Manen, 1990).

Interpretation from narrative description facilitates access to an understanding of the participant's experience of the phenomenon. In order to address this goal, analysis of data was guided by the procedures described by van Manen (1990). This method (see table 3.1) affords the researcher flexibility and initiative in their approach to interpretation and requires a deep commitment to the goal of gaining a deeper understanding of the study phenomenon.

The initial analysis revealed words and phrases that stood out as being meaningful within the overall participant story. After highlighting these meaningful words and phrases, it was necessary to relate those parts back to the whole of the transcripts in order to search for shared meanings, and differences. Here began the process of dialogue with the whole and the parts of the text, known as entering and re-entering the hermeneutic circle (Polkinghorne, as cited in Laverly, 2003).

Meaning units were drawn out and colour-coded within the text and questions and notes about meaning and pattern were written in the wide transcript margins. Ultimately, meaning units were aggregated into working themes, and accompanying relevant textual data and narrative were recorded alongside them. This process entailed deep thought and a rigorous deliberation upon the emerging themes and their meaning. I critically reviewed transcripts in search of alternate interpretation. I asked myself questions as did the thesis supervisor. For example: How did moving to a long term facility affect the meaning of the experience? Did being in the hospital for a prolonged time affect the living of the experience? Was suffering caused more by the loss of family ties, than the actual ventilator experience? What do the participants mean when they talk of freedom? Morse

describes the goal of the interpreter/researcher “as going beyond what is given directly” (1994, p.146).

The hermeneutic process of reading and re-reading and dialoguing with the text revealed a number of themes that began to represent the shared experience of the participants. In an effort to be as true to the meanings as possible, descriptions and stories were written and rewritten in an effort to include the meaningful themes within the context of the lived experience and ensure that they were presented as disclosed (van Manen, 1990). I continued to reflect on the degree to which the emerging interpretation was answering the research question: What was it like to transition to LTMV?

Reflection upon the working themes involved a process of inductive thinking or intuiting, which facilitated the reduction that revealed essential themes (Munhall, 1994). Themes were considered essential when they were revealed as being unique to the phenomenon of transition to LTMV and fundamental to the overall shared description of living the experience.

The writing process instigated more thought and reflection and a greater depth of understanding. Field notes were reviewed extensively and I reflected upon them throughout the data collection and analysis process. Preliminary and ongoing findings were summarized and discussed with my thesis supervisor. Ultimately, meaningful relationships and interconnections between essential themes were illuminated. In the end, this is what provided the scaffolding necessary for the interpretive construction of a comprehensive description of the meaning or essence of transition to LTMV.

Interpretation encompassed: the symptom experience of chronic respiratory failure; the event or events that precipitated the admission into hospital; time spent in the

hospital and in ICU; the experience of returning home to a community residence or relocating to a long term care facility; and the experience of life at home. Presenting the findings in this way facilitated the inclusion of contextual background from which to reveal the meanings that the participants attribute to their transition experience.

Descriptive statistics were used to analyze data from the demographic form and SF-12 health surveys were scored according to the procedures outlined by the author (Ware et al., 2005).

Measures of Rigor or Trustworthiness

Qualitative research methodologies cannot be evaluated by the same means used to measure reliability and validity within the quantitative paradigm (Emden & Sandelowski, 1999). However, it is necessary to demonstrate that all research projects are rigorous so that they may be adjudged to be credible. Several authors have proposed ways in which rigour can be measured in qualitative research using a phenomenological approach (Koch, 1994; Maggs-Rapport, 2001 & Meyrick, 2006; Munhall, 1994; van Manen, 1990).

Koch (1994) recommends that researchers provide a decision trail upon which trustworthiness may be established. An audit trail allows another researcher to follow the decision trail used by that researcher (Lincoln & Guba, 1990). In this study an audit trail was created through written discussion of methodological decisions; audio-tape recording of interviews; transcript records; written record of the evolution of data analysis; field note recordings and reflexive journaling.

Trustworthiness is manifest through dependability, credibility, transferability and confirmability (Guba & Lincoln, 1985). Credibility refers to the truth or the believability

of findings. Data saturation supports the credibility of the results (Guba & Lincoln, 1985). In this study, saturation occurred when there was ongoing replication of information concerning the emerging essential thematic elements. In an effort to ensure that I heard the voices of all individuals, who wished to share his/her perspective, I interviewed new participants, even whilst having the sense that saturation was being achieved. One potential participant, whose response was received late in October, was not interviewed.

Prolonged engagement with participants and data also enhances credibility. In this study, information-rich data were obtained through over 35 hours of participant interviews. Subsequent immersion with the data occurred for many months. Findings were discussed and reviewed with the thesis supervisor. Preliminary findings and interpretation were also discussed with participants during and following each interview. Discussion was particularly meaningful when multiple interviews had occurred with the same participant.

Transferability is a measure of the extent to which qualitative findings may be transferred to another qualitative study within a similar context. Dependability refers to the ability of research findings/interpretation to be repeatedly affirmed. This means of evaluating qualitative research is completed by participants and others familiar with the phenomenon of interest who read the research summary and report. Transferability in this study was addressed by making every effort to fully enlighten the reader of the processes that I used to arrive at the interpretation of findings. A detailed description of methodological decisions, and procedures; as well as logistic, operational and contextual matters has been provided.

Morse et al., (2002) recommend strategies to ensure that rigour is built into the research project at its inception, so that trustworthiness is not only evaluated post hoc, but on an ongoing basis. Investigator responsiveness, methodological coherence, theoretical sampling, sampling adequacy, an active analytical stance and saturation are the strategies purported to enhance rigour. These strategies were utilized early on, when making decisions regarding the design of this study, as well as during my ongoing attention to the six activities outlined by van Manen (1990).

In order to ensure trustworthiness, the procedures of verification and checking were undertaken through review and discussion of summarized findings with the project thesis advisor. In addition, maintaining an ongoing openness and flexibility to the data, during collection and analysis, served to assure that analysis is checked against the research question and the whole of the transcript data. The investigator, in collaboration with the thesis supervisor, endeavoured to continually reflect upon the data in order to question findings and seek alternate interpretations, while also being flexible to changing circumstances. The data were meticulously explored for negative cases. An audit trail was maintained in order to ensure that the process of data analysis was as transparent as possible.

I endeavoured to adhere to the criterion for trustworthiness as outlined by the chosen methodological approach of phenomenology.

Ethical Considerations

It is generally recognized that an ethical tension may exist when conducting nursing research with human participants. The tension arises from the potential conflict between the protection of human rights versus the generation of knowledge; the

'humanism versus science' paradox (Larossa et al, 1981; Lindsey, as cited in Ford & Reutter, 1990). The reality of ethical tension should be considered all the way through the research process, including during the dissemination of findings. In order to safeguard the rights of participants, respectful and carefully considered procedures, predicated on the ethical principles of autonomy, justice, non-maleficence and beneficence are implemented. The following section describes how ethical procedures were considered throughout this research project.

Ethics review

The purpose of ethics committees is to ensure that research abides by ethical principles. While boards scrutinize research proposals, it is ultimately the responsibility of the researcher to ensure the protection of all participants (Orb, Eisenhauer & Wynaden, 2001). In addition to being the investigator in this study, I am also a registered nurse who conducts client interactions according to the Canadian Nurses Association Code of Ethics for Registered Nurses. I had also signed a Privacy Health Information Agreement (PHIA) with the Health Authority. Permission to conduct this study was obtained from my research thesis committee, the Education and Nursing Research Board for the University of Manitoba (ENREB), and the research review boards of two health care facilities in a mid-western Canadian province (see Appendix A).

Autonomy

In upholding the principle of autonomy, I recognized and honoured the right for all participants to freely choose whether to commence and continue with participation in this research project and, once participation began, I continued to ensure that self-determination was protected.

Strategies to honour participant autonomy should ensure that participation is not only voluntary, but informed (Ford & Reutter, 1990). In this research endeavour such efforts included:

- (1) No dual relationships were present within the study.
- (2) Potential participants were initially notified of the study by letter or by individuals having no affiliation with the study. To prevent potential participants from feeling coerced, the investigator did not have access to any ventilator user or caregiver names until individuals had given permission to release their names, or contacted the investigator by e-mail or telephone.
- (3) Participants were adults, 18 years or older, who voluntarily consented to be interviewed
- (4) The nature of consent, including the right to withdraw at anytime, to choose not to answer any question, or to stop the interview at any time was reviewed often; prior to acquiring consent, and prior to every interview.
- (5) Interviews occurred at a time and location of the participant's choosing. Approximate length of time for each interview was discussed prior to receiving the participant's agreement to proceed.
- (6) Prior to consent, written description of the study purpose, methods of data collection and time commitments were discussed. My student status, thesis supervisor's name and credentials, and university affiliation were also described. Contact numbers for both individuals and the Human Ethics Secretariat were provided. Additionally, all the information was discussed

verbally and questions were answered. Risks and benefits were discussed prior to receiving consent.

Non-maleficence

Following the principle of non-maleficence requires the researcher to implement strategies to ensure that neither the researcher nor the research does harm. Application of this principle was carried out by maintaining an ongoing awareness that the very purpose and nature of phenomenological study meant that participants were vulnerable to remembering unpleasant or difficult experiences and to losing personal and family privacy.

In-depth interviews may present both risks and benefits for participants. In recognizing the unstructured and emergent nature of qualitative interviews, I recognized that definitive, informed consent, around the content and substance of interviews is not possible (Ford & Reutter, 1990; Orb et al., 2001). Therefore, discussion concerning the nature of the interview was detailed and participants were provided opportunities for questions. In addition, I reinforced the opportunity for the participants to withdraw at any time.

The possibility of participant distress meant that a plan for intervention needed to be in place prior to interviews. In the event that in-depth discussion resulted in unpleasant or disturbing memories, I planned to stop the audiotape, validate the individual's emotion, and provide time. If the response was evaluated as being more than transitory, I planned to suggest stopping the interview. My phone number was provided to all participants, and a prior arrangement had been made with health professionals who were available to counsel and debrief participants if necessary.

In this study, several participants demonstrated emotional responses to memories of transition to LTMV. None of the individuals wished to consult with the healthcare professionals assigned to assist. In all cases, the interview was stopped, the emotional response was validated and comfort was offered. In two cases, the participants required a few minutes to compose themselves. No individual chose to discontinue the interview or withdraw from the project, and all participants were able to recommence the interview in a composed and engaged manner. I followed up informally with the affected participants. No participant wished assistance from the assigned HCP.

Study participants required technological assistance in the form of ventilation, electric wheelchairs and, in one case, a communication device. The potential for fatigue and increased work of breathing was taken into consideration throughout the study. Within that context, participant's opportunity to discontinue the interview at any time was reinforced. Ventilated participants were also asked to please take their time and not feel rushed during their interview responses. During the consent process, all participants were provided with the option of shorter interviews. One of 18 participants requested shorter interviews.

One caregiver participant, who had signed a consent form, was very busy and an opportunity for an interview did not transpire. I recognized that it was important to be available, but not aggressive in pursuing the interview. Study participants may have difficulty openly withdrawing from a research project, and individuals may recognize their need to avoid in-depth discussion.

Beneficence

Benevolence is linked to non-malevolence; however, applying the principle of benevolence requires the researcher to go beyond the aims of non-malevolence, by not just “doing no harm”, but by “doing good” for others. In research, benevolence is often enacted through efforts to ensure that the research is of maximum benefit to participants. It is essential that one not misconstrue benevolence for paternalism, or determining what is best for another. Benevolence in this research project required that I make every effort to ensure that potential participants had sufficient knowledge to make informed, autonomous choices. Written and verbal information about the study was provided, potential risks and benefits were explained and I was open to questions and discussion about the research on an ongoing basis.

Informal conversation took place prior to and following each interview. Participants were often interested in the study and asked several questions following interviews. It was apparent that participants wanted their perspectives, stories and voices to be heard in a way that might improve the lives of future ventilator users and families. Those interactions highlight my responsibility to take seriously the obligation to disseminate findings as accurately and broadly as possible.

Justice

Justice refers to the ethical obligation to treat each person in accordance with what is morally right and proper. In the ethics of research involving humans, the principle refers primarily to distributive justice, which “requires the equitable distribution of both the burdens and the benefits of participation in research” (CIOMS. World Health Organization (WHO), 2002).

The long-term ventilator user population represents a group whose voice and

perspective is lacking in the literature. In addition, while there has been much study concerning cognitive impairment and the elderly residing in long-term care facilities, the same cannot be said for younger individuals, particularly those requiring LTMV. For this study, I endeavored to ensure that all ventilator users in the geographical study area had an opportunity to participate. Those with communication challenges were not excluded, and flexibility in data collection methods (as discussed earlier) was provided to address individual needs.

Confidentiality

In diminishing the potential burdens associated with participation in research, the investigator must be respectful of participant's right to privacy and implement strategies to ensure confidentiality. The issues of privacy, confidentiality and anonymity were discussed with all participants during the informed consent process. The study design (interviews) prohibited participant anonymity; however, efforts were implemented to ensure confidentiality.

A transcriptionist, who agreed to sign a confidentiality agreement, myself and my thesis committee supervisor were the only persons with access to the audiotapes. The only other individuals with access to the summarized transcribed interviews were thesis committee members. Transcribed interviews were only identified through a code number. Consent forms were/are kept in a locked drawer, separate from another locked filing cabinet where the transcribed audio taped data files, and coded field notes are stored. No identifying information is present on any of this material. Data collection forms, field notes, transcripts and audiotapes will be kept for a period of seven years, at which time, data will be destroyed.

Matters of confidentiality and risk for identification were particularly significant in this study, given that many of the participants distinguished themselves as members of a small and distinct population of ventilator users. This reality, and concerns related to confidentiality, was discussed with participants prior to and during the consent process, as was the strategy to alter some detail, and information. Virtually every participant indicated that identification was not a concern foremost in their minds. Despite this, every effort was made to ensure confidentiality.

All participants were assigned a pseudonym, and identifying information was altered when it was believed to put the participant at high risk for identification. For example, in many instances participants were not identified with a specific disease condition. The pseudonyms used in the narrative data were not used for presentation of SF-12 data. Some detail and richness of description were excluded from the presentation of participant stories. Some data were distorted, when necessary, to minimize the likelihood of tracing information to any of the participants. Additionally, in order to ensure confidentiality, no reference to either the geographic study location or to hospital names will be provided in any future publication or presentation of the study.

Participants were informed that I was bound by the Protection of Persons in Care Act, and was obliged to report any evidence or description of abuse (financial, physical, and sexual).

Risks and Benefits

In addition to the risks discussed earlier, there may be some benefit to sharing one's story and engaging in a process that is ultimately targeted to assisting others. According to van Manen (1990), the intense conversations that characterize many in-

depth interviews may have lasting affects on participants, and “may lead to new levels of self-awareness, possible changes in life-style, and shifting priorities of living” (p.162). There were no tangible benefits or financial compensations for participation in this study. Information, knowledge, and understanding generated from this study may enhance the care of persons living with CRF who will require LTMV and their family and informal caregivers.

Study Limitations

The participants recruited for this study were not necessarily representative of the overall population of persons transitioning to LTMV. In particular, there were a disproportionate number of female ventilator users, when compared with males, and all ventilated participants were invasively ventilated via tracheotomy, thus perspectives of non-invasively ventilated persons is lacking.

The sample size was purposefully limited in order to gather rich depth of narrative data. While the study design was not intended to generate statistically significant results, the findings from this study may serve to help clinicians understand the complex phenomenon of transition and reliance on respiratory technology, affording them new insights into the perspectives of their patients.

Chapter Conclusion

This hermeneutic phenomenological study was designed to gain an understanding of what is it like to transition to the stable reliance on LTMV. Data were gathered through in-depth, semi-structured interviews, demographic and health survey questionnaires and field notes. The research setting was in the participant’s home or in a private location in a post secondary institution. Qualitative data analysis unfolded

according to Van Manen's human science method for hermeneutic phenomenology (1990). Analysis occurred concurrent with data collection, and sample size was determined through an ongoing evaluation of how comprehensively research questions were being answered, and whether redundancy and saturation were being realized. The significance of establishing rigour and the strategies to achieve it were discussed, as were ethical dimensions and study limitations.

CHAPTER FOUR: DEMOGRAPHIC FINDINGS

Introduction

This chapter presents a description of the demographic profile and health survey information of study participants. Ventilator users will be described first, followed by family caregivers.

Description of Participant Sample

Ventilator users

Eleven individuals who had experienced transition to LTMV at least six months prior to the commencement of study were recruited. Of the eleven participants, nine were female and two were male. Participants required mechanical ventilation for the treatment of chronic respiratory failure resulting from a variety of causes as follows: neurological/neurodegenerative/neuromuscular disease, thoracic wall deformity, central hypoventilation syndrome, polio/post-polio syndrome, and quadriplegia. At the time of data collection, all participants were ventilated invasively, via a tracheotomy tube, and utilized an LP10, LP6 or LTV model of mechanical ventilator. Several participants had utilized non-invasive ventilation systems during the years preceding their tracheotomy.

One of the eleven participants was self-employed, two were retired, and one was a homemaker. The remaining participants were unemployed as a consequence of the restrictions imposed by their primary disease, or their utilization of mechanical ventilation. Of the eleven participants, one was able to walk independently, while three were able to ambulate for short distances. All participants used mobility devices; the majority requiring an electric wheelchair. One participant reported requiring frequent tracheal suction. The majority of participants required suction on an occasional basis

only.

Table 4.1

Ventilator User-Participant Sample Description

Characteristic	Number (%)
<u>Age</u>	
Age range	40-88 years
Mean age	61.3 years
40-55 yrs	4 (36.0%)
56-65 yrs	4 (36.0%)
66-88 yrs	3 (27.3%)
<u>Gender</u>	
Female	9 (81.8%)
Male	2 (18%)
<u>Place of residence</u>	
Urban (total)	8 (72.7%)
Rural residence, > 70km from urban centre	3 (27.3%)
Long term care	5 (45.5%)
Community residence (home or apartment)	6 (54.5%)
<u>Marital status</u>	
Married	5 (45.5%)
Single	2 (18%)
Widowed	2 (18%)
Divorced	1 (9%)
Separated	1 (9%)
<u>Reported annual household income</u>	
< \$10,000	7 (63.6%)
\$10,000-\$20,000	2 (18%)
\$21,000-\$30,000	1 (9%)
>\$70,000	1 (9%)
<u>Ethnic background</u>	
Aboriginal/First Nation/Inuit.	2 (18%)
Canadian	9 (81.8%)

Table 4.2

Description of Ventilator Utilization

Characteristic	Number (%)
<u># of years of invasive ventilation</u>	
Range	2-21 years
Mean	7 years
<u>Ventilator utilization</u>	
24 hour/day utilization	8 (72.7%)
Nocturnal/sleep ventilator utilization only	3 (27.3%)
<u>Utilized non-invasive ventilation prior to tracheotomy</u>	
	7 (63.6%)
<u>Types of non-invasive ventilation used</u>	
	CPAP, BIPAP, Rocking bed, Iron lung, Chest shell
<u>Home assistance (6 community living individuals)</u>	
Infrequent assistance (< 1x/mos)	1(9%)
Daily home care (nursing/allied health)	1 (9%)
18-24 hour attendant (non-nursing)	4 (36.0%)
<u>Oxygen utilization (total)</u>	
	5 (45.5%)
Occasional use	4 (36%)
Frequent use	1 (9%)

Ventilator User Health Related Quality of Life Survey Information

The Medical Outcome Studies Short-form 12, version two (SF12v2) health survey was completed with each participant prior to their first audio-taped interview (see Appendix N). Participants were asked to respond to survey questions by indicating how they generally felt over the month preceding the interview. Scores on 12 items were added and transformed, according to the author's formula/instruction. Physical (PCS) and mental component summary (MCS) scores were calculated.

The sample size for this study was purposefully small, as the overarching purpose of the study was to develop a detailed description of the meaning of transition to LTMV.

The purpose of piloting a generic, norm based survey tool was to enable the investigator to compare ventilator user scores with those of their family caregiver, and norm based scores of those living with a variety of chronic illnesses. Because the participant numbers were small, statistical significance was not achievable.

The form required about two to five minutes for participants to complete. Six of the eleven participants dictated their responses to the investigator, while five participants completed the form independently. Two participants pointed out that their responses would have been less positive had they been asked to respond earlier in the trajectory of their transition experience. They indicated that access to transportation and acceptable attendant assistance were pivotal factors in their positive assessment of health and wellbeing. Those comments reinforced the notion that SF-12 scores do not reflect transition, but the participant's self measurement of health at the time of the interview.

Findings

The health survey revealed very low physical functioning scores for VAI (see table 4.3). Raw scores were measured at, or near, zero. Despite this, ten of the 11 participants rated their overall health as good, very good, or excellent; and none rated their health as poor. When VAI mean scores were compared with those of individuals living with chronic kidney disease, VAI scores were higher in all domains, with the exception of the physical functioning and PCS (see figure 4.1).

Mean mental component scores (MCS) were similar or better than those of individuals living with other chronic illnesses such as chronic kidney disease (CKD), diabetes or heart failure. However, two VAI participant's mental health scores were below the value identified for individuals living with depression (see table 4.3). One of

those individuals had experienced a very recent move to a LTC facility, and had articulated a great sense of loss and sadness concerning personal independence. The second individual expressed significant uncertainty about her continuing ability to live independently, and articulated concern about the health status of her primary caregiver. (See table 4.3). Mean data are expressed as mean +/- SD.

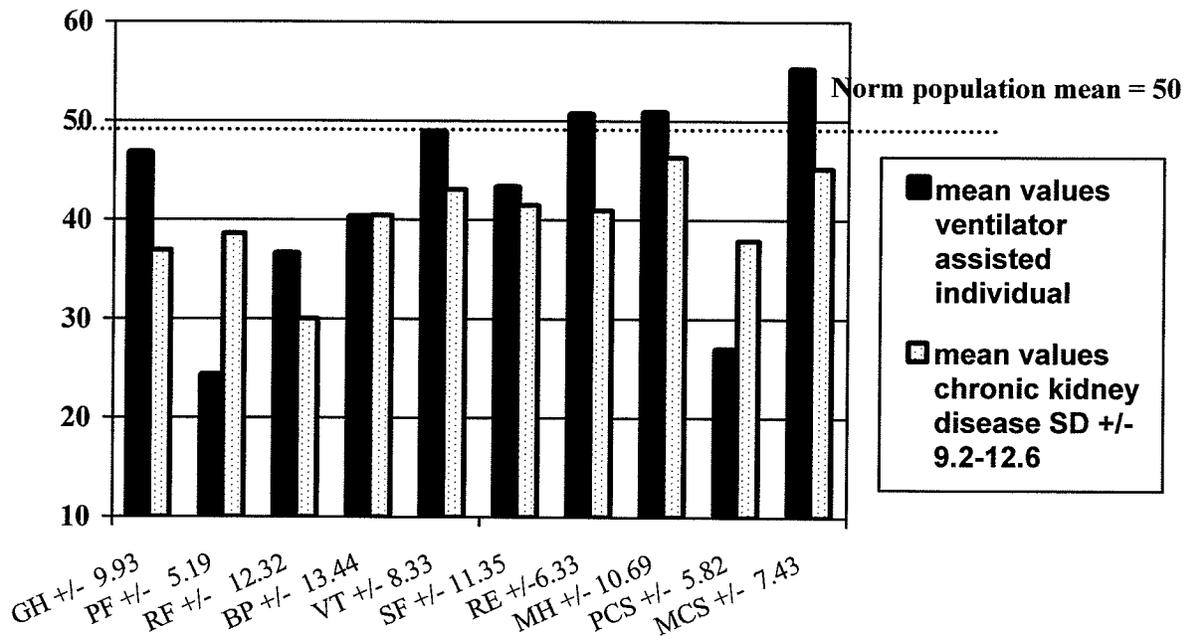
Table 4.3

Ventilator User SF12v2 © Eight Domain Scores, Physical and Mental Component Scores

VAI Participant	General Health	Physical Functioning	Role Functioning	Bodily Pain	Vitality	Social Functioning	Role Emotional	Mental Health	Physical Component Score	Mental Component Summary
A	55.52	22.10	20.32	47.25	57.81	46.46	56.07	58.44	23.01	65.76
B	44.74	22.10	38.74	47.25	47.74	46.46	44.89	34.06	31.02	45.93
C	44.74	30.69	38.74	57.44	47.74	56.56	56.07	58.44	33.30	61.03
D	33.95	22.10	20.32	47.25	27.62	16.17	56.07	58.44	16.98	50.85
E	44.74	22.10	57.17	57.44	57.81	36.37	56.07	64.54	35.23	60.06
F	55.52	22.10	38.74	47.25	57.81	56.56	44.89	52.34	27.51	58.74
G	29.64	22.10	57.17	47.25	47.74	36.37	56.07	52.34	30.66	53.58
H	61.98	22.10	38.74	26.86	47.74	46.46	50.48	52.34	26.74	57.61
I	44.74	39.28	38.74	26.86	47.74	46.46	39.30	58.44	30.53	52.07
J	44.74	22.10	38.74	26.86	47.74	36.37	44.89	27.96	28.9	41.14
K	61.98	22.10	20.32	16.67	57.81	56.56	56.07	46.25	17.52	65.60
VAI Mean	46.72	24.27	36.54	40.27	48.82	43.27	50.64	50.82	26.90	55.18
+/-	+/-	+/-	+/-	+/-	+/-	+/-	+/-	+/-	+/-	+/-
+/- SD	9.93	5.19	12.32	13.44	8.33	11.35	6.33	10.69	5.82	7.43
Norms in CKD	36.93	38.64	30.02	40.46	43.09	41.49	40.97	46.32	37.88	45.18
+/-	+/-	+/-	+/-	+/-	+/-	+/-	+/-	+/-	+/-	+/-
Norms for Diabetes	11.53	11.76	10.70	10.85	9.20	11.25	12.61	10.31	11.17	10.13
+/-	+/-	+/-	+/-	+/-	+/-	+/-	+/-	+/-	+/-	+/-
+/-	10.44	11.57	11.49	11.41	10.33	11.68	12.72	10.47	11.07	10.72

Figure 4.1

Ventilator User, Chronic Kidney Disease: SF-12 Mean Score Comparison



Family Caregivers

Seven adult family caregivers of ventilated individuals were recruited. Five spouses, one sibling and one adult child of ventilator user participants described themselves as family caregivers and agreed to share their stories of being with and caring for their family member as they transitioned to LTMV. There were four males and three females in the sample (See table 4.4). Four participants were spouses residing with the ventilator user. One spouse resided in the family home, while the ventilator user lived in a long term care facility, and two participants (sister and adult child) resided in their own family home with their respective spouses. Two participants described themselves as being retired, four participants were employed outside of the care giving arrangement and

one participant was currently employed as a caregiver for his/her family member, but had previously been an unpaid caregiver.

It is important to note that not all ventilator user participants had a family caregiver and three of the eleven ventilated participants in this study revealed that they had experienced a significant loss of relationship during their transition to LTMV.

Table 4.4 *Family Caregiver -Participant Sample Description*

Characteristic	Number (%)
<u>Age</u>	
Age range	26-72 years
Mean age	62.7 years
<u>Gender</u>	
Female	3 (43%)
Male	4 (57.2%)
<u>Relationship to ventilator user</u>	
Spouse	5 (71.4%)
Adult child	1 (14.3%)
Sibling	1 (14.3%)
<u>Caregiver Residence</u>	
% Residing with ventilator user	4 (57.2%)
% Residing independently from community dwelling VAI	2 (28.6%)
% with VAI residing in LTC	1 (14.3%)
<u>Employment status</u>	
Retired	2 (28.6%)
Employed outside of caregiving relationship	4 (57.2%)
Paid as caregiver	1 (14.3%)
<u>Annual family income</u>	
\$21,000-30,000	4 (57.2%)
\$31,000-40,000	2 (28.6%)
over \$70,000	1 (14.3%)
<u>Self-reported hours of caregiving per 24 hours at the time of interview</u>	
0 hours	1 (14.3%)
Occasional	1 (14.3%)
3-4 hours	1 (14.3%)
Varies: 0-24 hours	3 (43%)
8-10 hours	1 (14.3%)

The SF-12 health survey

The SF-12 health survey questionnaire was completed by family caregivers. With the exception of physical functioning scores, variability in scores was more prominent in the ventilator user group than the caregiver group. One caregiver lived with a visible disability, which necessitated the use of an electric wheelchair, and this is reflected in the outlying physical function score. General health scores were only slightly higher in the caregiver group, when compared with the VAI group, and most caregivers rated their health as being good to very good. However, mental health and MCS scores of five of the seven VAI/caregiver dyads were lower for the caregiver than for the ventilator user, but not substantially different from the norm of the healthy population (See table 4.6).

Table 4.5

Family caregiver SF12v2 © eight domain scores, PCS and MCS scores

VAI Participant	General Health	Physical Functioning	Role Functioning	Bodily Pain	Vitality	Social Functioning	Role Emotional	Mental Health	Physical Component Summary	Mental Component Summary
L	55.52	56.46	57.17	57.44	67.87	46.46	50.48	52.34	56.46	49.30
M	44.74	56.46	57.17	47.25	57.81	36.37	44.89	46.25	52.74	41.4
N	44.74	39.28	52.56	47.25	47.74	46.46	56.07	46.25	42.07	49.71
O	44.74	56.46	57.17	57.44	57.81	56.56	56.07	64.54	50.39	58.17
P	55.52	56.46	47.96	47.25	57.81	46.46	44.89	40.15	53.47	40.71
Q	44.74	56.46	57.17	57.44	47.74	56.56	50.48	40.15	56.56	41.5
R	44.74	22.10	47.96	57.44	57.81	56.56	56.07	58.44	33.93	64.24
Caregiver Mean	47.14	48.71	53.43	52.71	55.57	48.86	50.86	49.43	48.86	48.86
+/-										
SD	4.97	12.38	4.40	4.94	6.39	7.0	5.0	8.4	7.83	8.6
VAI Mean	46.72	24.27	36.54	40.27	48.82	43.27	50.64	50.82	26.90	55.18
+/-										
SD	9.93	5.19	12.32	13.44	8.33	11.35	6.33	10.69	5.82	7.43
Norm pop. males and females age 55-64	48.27	47.61	48.26	48.79	50.21	49.93	49.83	51.40	46.90	50.84
+/-										
SD	9.19	9.40	9.25	9.58	8.94	9.06	9.06	8.74	9.18	8.56

Table 4.6

Family caregiver/VAI dyads
Mean MCS score comparisons

VAI/Caregiver Group	VAI	Caregiver	Kidney disease Mean +/- SD	Depression Mean +/- SD	Healthy pop. Mean +/- SD
1	65.76	49.3	45.1 +/- 10.13	37.40 +/- 10.76	50.84 +/- 8.56
2	65.76	41.56	45.1 +/- 10.13	37.40 +/- 10.76	50.84 +/- 8.56
3	45.93	40.71	45.1 +/- 10.13	37.40 +/- 10.76	50.84 +/- 8.56
4	61.03	41.04	45.1 +/- 10.13	37.40 +/- 10.76	50.84 +/- 8.56
5	50.85	49.71	45.1 +/- 10.13	37.40 +/- 10.76	50.84 +/- 8.56
6	58.74	68.24	45.1 +/- 10.13	37.40 +/- 10.76	50.84 +/- 8.56
7	53.38	58.17	45.1 +/- 10.13	37.40 +/- 10.76	50.84 +/- 8.56

Conclusion

Chapter four described the participant sample of eleven ventilated individuals and seven family caregivers. A greater number of females were represented in the VAI sample; however there was diversity in the age of participants, and the disease conditions underlying CRF. As well, a variety of formal and informal caregiving arrangements were represented. Participants residing in both rural and urban locations, as well as a LTC facility were included in the sample. All ventilated participants were invasively ventilated at the time of study; although many had prior experience with NIV systems.

The SF12v2 health survey was also described, as was the rationale for its use and presentation within the demographic section of this qualitative research project. Due to a purposefully small sample size, findings from the SF-12 survey were not statistically significant. However, it is evident that despite very low physical functioning and PCS scores, the other health domain scores for VAI were equal to, or higher than the mean scores reported for individuals living with chronic kidney disease or diabetes. In addition, the general health scores of ventilated participants in this study were within one standard deviation of the mean of the “normed” healthy population, and their MCS scores were slightly higher than those of the mean “normed” healthy population. In summary, the ventilated participants in this study report good HRQOL, despite significant functional impairment.

In five of seven VAI/caregiver dyads, the ventilator user MCS score was greater than that of their caregiver counterpart; however, the general health scores for both groups were similar. Further discussion of these findings will be presented in chapter eight.

CHAPTER FIVE: VENTILATOR USER FINDINGS

Introduction

This chapter presents the findings of this phenomenological study that explored the lived experience of transition to long term mechanical ventilation for individuals with chronic respiratory failure. The question that this chapter answers is: How do individuals with chronic respiratory failure experience transition to LTMV? In answering this question, an overview of two ventilator user participant stories is presented, followed by a detailed thematic analysis of the meaning of transition to long term mechanical ventilation (LTMV) for ventilator users.

Although unique aspects of each participant's story of transition to LTMV are evident what emerged, through analysis, were shared meanings and essential elements of the experience of transition to LTMV.

Ventilator User Stories

In telling the story of transition to LTMV, participant's spoke about their chronic illness experience. For some this meant that their stories bridged a good deal of their lifespan. Each participant provided a distinct and rich description of his or her illness and transition experience, thus enabling me to arrive at an interpretation story that included the social, historical and cultural context of each participant's experience.

Although there were eleven ventilated participants in this study, I have not included every story. Instead, I have chosen an overview of the stories of two participants as examples that stand out as paradigm cases. Benner (1984) refers to a paradigm case as one that stands out and facilitates the acquisition of a rich understanding.

In detailing participant stories, it was important to maintain their authenticity,

while also making every effort to ensure confidentiality. Therefore, several strategies were implemented to decrease the potential for participant identification including: the use of pseudonyms, the selection of narrative examples less likely to disclose the participant's identity to the reader, and alteration of specific information (ages, dates, gender).

I have selected the following stories for two reasons. First, they provide an apt representation of the main thematic elements of the lived experience of transition to LTMV. Secondly, the following stories exemplify both the complexity and uniqueness that is inherent in lived human experience. The following section details the stories of Rose and Margaret (*randomly assigned pseudonyms*).

Rose's Story

Rose lived independently in an urban community. I interviewed her three times and each time I was greeted at the door by one of her lay attendants. On two occasions, Rose sat in her wheelchair and she invited me to sit at the table across from her. On our third meeting, Rose was in her bed, reading a book and listening to music. I learned that Rose was very cognizant of the need to care for her body, as she explained that she needed to ensure that she had days of rest and relaxation, so that she could stretch out on her air bed. She explained that she had been busy with several meetings over the course of the week, and as a result she had been up in her wheelchair for long periods of time.

Rose was ventilated via a tracheotomy and she wore a scarf covering her neck. Her hair and make-up were immaculate and she had a tremendous presence. She told me that she had a neuromuscular condition that was diagnosed when she was a young girl.

As a result, she had a long history of making adjustments to the way that she lived her life:

Yeah, I've had, you know, went from being . . . like mobility things, like having poor balance, I'd fall easily. And then I went to using crutches and leg braces. And I went to using a manual wheelchair and then eventually an electric wheelchair. But I was always able to use the, my crutches for exercise . . . up until I was seventeen (Rose, 202-207).

Rose began our first interview by talking about her experience with chronic respiratory failure. She had initially noticed problems with her breathing at about the time of her graduation from high school. She explained that she had been very busy and involved with activities at home and school, thereby attributing her fatigue to "being run down".

Her symptoms of fatigue and somnolence were not dramatic, painful, or acute in nature, and their significance only became apparent in hindsight. As Rose adapted her lifestyle to her diminishing level of energy, she became less able to engage in the world:

That last year I noticed it really getting tougher to do things. And that last few months definitely harder (Rose, 65-67).

At some level I probably did know that something was wrong with my breathing but I, I kept attributing it to being tired, you know (Rose, 40-41).

Rose indicated that she had once done a project in biology about her disease:

And so I kinda knew what the prognosis was although I didn't really want to believe it. That kind of information did skim my mind at the time but, uh, you know, I was out really late the weekend before . . . I'll just make sure I sleep, you know, get lots of rest and not do anything for the weekend (Rose, 43-45, 55-57, 63-64).

She recalled feeling very sluggish, anxious and short of breath. Her co-worker became concerned:

And one of my coworkers said, you know, you don't look too good, maybe you should try to phone, make an appointment with your doctor (Rose, 67-68).

Rose second guessed the cause of her symptoms, believing that there must have been a benign reason for them and so it was her co-worker who flagged Rose's symptoms as being of concern, thereby motivating her to see her physician:

Rose's physician was alarmed by her condition, however Rose was not sent to the hospital in an ambulance, but in a handi-transit vehicle. Rose had never been referred to a respiratory specialist for diagnostic assessment or consultation:

She (GP) basically took blood and listened to my chest, took some x-rays, that sort of thing. And then she came back in the room and she looked at me like she was looking at a ghost basically. And she was like saying to me, how are you feeling? Like she was all concerned and whatever. And I says, well, you know, I've felt better--laughs (Rose, 103-108).

So that was the ride that I took with the handi-helper driver. He said that, uh, he was all like kinda freaking out. I guess I must have been breathing labouring or I guess my colour was off and what not. So it was visible that I did not look well (Rose, 112-116).

Rose described her experience of a progressively altered consciousness:

At this time I had no idea what respiratory people were or anything. So, um, they called themselves the respiratory tech, whatever, and they took a blood gas which I never had before. And, holy crap was that sore. And then they came, somebody came back and gave me some oxygen . . . I started feeling like I was dying. I felt like really scared. And I didn't know what was happening. Well I did, but I didn't. Do you know what I mean? (Rose, 124-129,136-138).

. . . It felt like it was going to be the end (Rose, 143).

And I remember it sounding like he was a million miles away and through a long tunnel kind of thing. . . It felt like I had a thousand pounds sitting on my chest or something. I'm like trying to push it off; this imaginary boulder. . . . And then I was gone (Rose, 147-148,150-156).

Rose recollected having people on either side of her stretcher and the physician saying "squeeze my hand". She recalled that when she "came back" she was in an ambulance and she was being transferred to a second hospital. She had an endotracheal tube in her throat, and she was being hand ventilated. Rose was admitted into a world of

intervention that was the intensive care unit (ICU), and she vividly recalled the experience of having “tubes” inserted:

I was like I can feel everything and just freaking out. It's like what's happening to me, you know. It's like what the hell am I thinking, I actually came back. Like I mean they would tell me, they would say to me, you know, we're going to put this in and what it's for and like that sort of thing. But, you know, and then they would say you know, swallow so it'll go in easier and it's like how am I supposed to concentrate on one part when they're in the middle of trying to put in the . . . so a blood gas in my groin and they're like jabbing me right in the nerve endings and they're trying to shove this thing, feels like it's going to go right into my brain. Are you crazy? It's like, OK, OK, wait, wait. I just wish they would give you a chance to have a breather in between, between things. And then you can't say anything. It's like more traumatic than anything (Rose, 324-335,351-352).

Rose recalled being intubated and on the ventilator as a most difficult experience.

She had trouble synchronizing with the machine:

They are trying to tell me how to do it. But I mean I was trying to take their advice and it wasn't working (412-403). It was like, it was foreign. Very foreign, you know, like having something pushing air into you and, you know, I had to really focus on trying to relax. And they kept saying that, you know, don't bite the machine, whatever, eh. And it's like; I didn't think I was biting it. I thought I was trying to breathe. But I guess because the alarms were going off all the time I guess I was but, hey, it was that I just couldn't find the rhythm of the machine. 'Cuz you're still, your body is still trying to breathe. Finally what I had to do was I'd get them to put the respirator so I could see it. And then when I could see it and I was watching, then I could get the rhythm of how it works. And then I was able to let it work properly (Rose, 384-393; 403-412).

Rose was not able to wean from mechanical ventilation and she remembered being very uncertain about what a tracheotomy would mean for her:

I was quite vain and what not and I didn't, you know. The thought of having this hole in my neck. Oh was it going to have to be there forever? Like you know questions like that (Rose, 424-427).

She needed time to adjust psychologically to the altered body that had been created by the tracheotomy:

I couldn't even look at it actually for the first six months. I couldn't look at it period. I refused to touch it. I wouldn't do the care. They had to do the care. I didn't want to (Rose, 509-511).

Rose worked hard to overcome communication challenges:

I was about three months in Intensive Care, very determined to learn how to speak, by the way, and get the cuff thing out and all that. I learned quite fast. They told me that you're very quick. You don't even sound like you're on a respirator (Rose, 1228-1232).

She had an awareness of being near death, and within that context she was confronted with an altered body and a struggle to breath on the ventilator. As her breathing slowly synchronized with the ventilator and she made the physical adjustment to being ventilated, she experienced an overwhelming sense of loss.

Rose experienced a paradox where life and renewed vigour coexisted with loss and an awareness of new restrictions. Rose explained that there were far more than physical adjustments required when transitioning to LTMV. She spoke of her emotional adjustment and she described what the transition experience had particularly meant for her:

Aside from the physical stuff that you, a person has to adjust to like having a trach and the whole thing of suctioning, the machine and all that sort of thing. And what not, there is something else that's very important and that's having intimate relationships (Rose, 537-542).

Rose spoke of the loss of a relationship that had occurred during her transition experience. She spoke of feeling powerless:

It didn't end up working out because of something . . . not to do with my personality or a bad relationship or, you know, we didn't get along or we were fighting all the time or that sort of thing. But it was because of something that I physically, I could not control. I had no control over ending up on a respirator, you know. It was a reality that I had to deal with. And, uh, unfortunately that reality requires a person to be pretty brave. The partner. Right? (Rose, 558-566).

She described experiencing the time of loss as a time of depression:

Basically {I was} in a depression and I didn't want to eat and I wasn't wanting to get out of bed. And I was quite upset and I didn't want anyone talking to me or whatever (Rose, 722-724).

Yea, yea, I just needed time to digest everything. Go through my feelings. I was hurt. I was angry and it didn't seem fair at all this sort of thing. I thought, you know, like this respirator is ruining my life (Rose, 580-583).

While still hospitalized, Rose felt as though the restrictions imposed by the respirator were causing her to lose so much of what she had worked for. She was unable to complete her degree because of her initial protracted hospitalization:

People who live in hospital aren't allowed apparently to go to college at that time (Rose, 606-608).

Lack of suitable housing became one of the issues that resulted in a protracted hospitalization of several years. During her hospitalization, Rose found it difficult to convince health care providers to alter their routine in order to provide her with some independence. Rose wanted them to understand that the hospital had become her home:

I lost my apartment. I worked so hard (Rose, 592-593).

I was feeling very caged, being very smothered and stifled. And that I was losing my own sense of who I am and that, you know. And it was making me hurt inside. And it was making me angry (Rose, 1058-1062).

A nurse had spoken to Rose in an effort to encourage her:

And basically they didn't know how to deal with me and one of the nurses extended herself and she was close with me. Had developed a bit of a relationship. And, uh, and basically came in the room slammed the door and, you know, suggested I don't give up. You can't, you know, you can't give up kind of thing. Like you've worked so hard and whatever (Rose, 727-737):

Rose began to struggle for independence. She railed against a system that told her “we know what is best for you”. She struggled for self-determination and autonomy.

Rose related that she was a very young person when she began meeting with people and she . . . *learned how to lobby for my own rights (Rose, 748-749).*

She recalls becoming energized by her self-advocacy efforts:

And then when I got so busy with all the advocating thing, that really kind of gave me motivation, right (Rose, 775-777).

I had to go through all this testing, whatever, and try to, basically show, to prove that I could achieve this intellectually, physically. And physically. Right. So I had to write all these tests and I had to perform all these manual things to show dexterity and this, that and the other. It was like three weeks I had to get up at 0530 in the morning and I was there from eight 'til three everyday. And the head nurse organized and made sure that the nurses got me up and did that. And he himself would come and pick me up at 3 o'clock. . . . It was like a prep, preparation. And it was all part of documenting and proving that, that I would be able to do, to live out in the community and that, you know (Rose, 786-796; 810-812).

Rose wanted to live independently and she stated that she was "willing to go to the ends of the earth to do whatever she had to do in order to get it" (Rose, 824-825).

Living independently is like breathing to me. You can't do, go without it. You know it's like having your own self-determination and, uh, to feel you have purpose in life is key to most people, I would think, you know. If you feel, a human being feels that they have no purpose, what is, why are we existing then? You know, just to be alive and on a respirator is not good enough for me. And watch, sitting and watching TV all the time is not quality of life to me. Like I want to participate in the world around me. . . My dream was to be what most people strive to be. To contribute (Rose, 830-839,846-849).

Having made a successful case for independent living, Rose was "going home":

There was a sense of family among the chronic patients. And definitely with the nursing staff (Rose, 881-883).

She eagerly anticipated her future; however, she experienced feelings of both excitement and loss:

I was so excited. I mean I had to get the heck out of there, just get on with things But at the same time I felt like I was leaving, leaving my family for the first time. I left with a sense that I was respected and I was on my own. And they were letting me go and wanting good things for me (Rose, 1101-1104; 1118-1120).

Within the context of her protracted hospital stay, Rose recalled the importance of caring for the whole person; of nurturing the human spirit:

Sometimes the person {the patient} just wants to be heard you know? It helps feed the human spirit. You can feed the spirit by having a sense of humour

with the person, you know, having a little bit of a 'ha ha' in your routine and that can really make a day. It's like instead of it all being just so focused on, you know, like oh we're here to change the circuits now. It's time to get your suction. OK. Got to do the trach care. And it's like, you're not defined as a human being; by just the things you require medically (Rose, 948-955).

She explained her view that the most significant positive contribution a health care provider can make to the adjustment process was recognizing and validating that patient as a whole person:

Above all else, the person's human first. Humans need to be heard. We need to feel that what happens to us matters.. And that just because you have been diagnosed with a condition that's supposedly terminal does not mean that you (should think) OK, well this persons expendable. Well they're already written off sort of thing. But I'm sorry to say that there is an element of that (Rose, 1657-1663).

Rose believed that the most significant experience in her transition was the struggle and process that ultimately resulted in her being able to live independently:

The main transition was to get back on track in what I felt was my life, you know (Rose, 1241-1242).

She described the respiratory crisis as a major event and after that event there was a process of “*adjusting to the event and to life*” (Rose, 1263-1264). Significantly, Rose identified that the adjustment had a lot to do with the attitudes of the people around her at that time:

How people will treat you and how, you know, are you encouraged to try to get back having a life or are you encouraged to say that this is it and I'm going to go to long-term care, you know. Like even if you are going to go to LTC, you know, are you encouraged to do things that you liked to do prior to you know . . .? Like, it's amazing how much you can do from a bed (she laughs) (Rose, 1256-1270, 1275-1276).

Rose spoke of courage; the courage required of the partner of someone living on a ventilator, the courage required to be ventilated and, ultimately, the courage required to go through transition and struggle for one's independence:

I already had that {courage} to begin with so mind you I had to, I really found out what I was made of when I went through the experience for sure. And to tell you the truth, the only thing that I thought about at that age was, get out and get free (Rose, 1445-1449).

I didn't think about what happens if the respirator breaks when you're in the middle of the highway in a foreign city. Or I didn't think about all that kind of stuff. I always thought, you know what, I'll just deal with it when it happens (Rose, 1457-1464).

For Rose, the transition to LTMV began at a time when she was just getting ready to journey into her adult life. She had worked hard, she was excited about the prospect of attending university and she was in love with a young man. She experienced symptoms of chronic respiratory failure, but she pushed niggling thoughts that fatigue might be something more than just being run down into the back of her mind. Respiratory crisis ensued and Rose's world came crashing in around her.

Rose experienced loss and she withdrew from the people around her, as she became depressed and irritable. After a period adjusting to being mechanically ventilated and thinking about her future, she developed a new resolve to make a life for herself. She was connected with people who encouraged and assisted her to challenge a pre-existing system that said "one cannot live independently on a ventilator".

Mechanical ventilation sustains Rose's life, but the ventilator does not sustain the human being; the "self", that is Rose. The meaning of the experience of transition to LTMV is embedded within Rose's determined struggle that ultimately facilitated her freedom and opportunity to live independently on a ventilator. Rose participates in the world, challenging herself to learn and assist others. She continues to hope for love and intimacy in her life. Her story illustrates that transition is about moving from a crisis event, through a period of great struggle and challenge, to a sense of freedom.

Rose also spoke of her long experience living independently on a ventilator and the triumphs and challenges in her life. Her story illustrated that adjustment to living on a ventilator was not a fixed event, but a dynamic one. She offered many insights about transition and adjustment that will be detailed, along with those of the other participants, in chapter seven.

Margaret's Story

Margaret is a middle-aged woman who was born with a neural tube defect. She has never been able to walk and she has experienced many surgeries and hospitalizations over the course of her life. Margaret is married and she and her husband live independently. Margaret has lay attendants who provide 24 hour assistance with ventilator and body care.

Margaret told me that *"this ventilator problem came quite out of the blue for me"* (Margaret, 82-83).

She described her experience of symptoms:

It was basically headaches, like it's like a migraine. I couldn't sit. I couldn't sit in a lit room. I couldn't have Bob talk to me a lot. I couldn't stand the music. I couldn't stand talking loudly. Or I couldn't even stand the air around me kind of thing, um, because like having an open door and the air coming at me was just too much (Margaret, 128-134).

My breathing problems I didn't feel were detrimental as much as my headaches started (Margaret, 16-17).

She discussed her headaches with her physician, who speculated upon a number of potential causes for them including: spine and neck deformity or neck tension from being in a wheelchair. However, at no time were ventilation issues explored and Margaret had not been referred to a respiratory specialist or undergone any diagnostic study:

And I didn't feel he, like he didn't. I felt he didn't consult with other doctors or anything like that about what the problem is because I would go back to him each

month. . . And, oh they're just bad. They are getting worse and stuff (Margaret, 22-26).

Margaret described other symptoms:

I was like just very, I was, and I would wake up basically like drunk. I'd be incoherent. I couldn't see properly. I couldn't, I couldn't talk to Bob very well. And it came to the point where I ended up putting myself in hospital (Margaret, 26-30).

Her life had been profoundly affected by the manifestations of CRF. On reflection

Margaret recognized that she had been experiencing symptoms for years:

Yea, between the time that it first started and the time that we actually knew what was happening, it was years (Margaret, 203-204).

When Margaret ultimately received assistance for CRF, her body was in a crisis state. She recalled awakening in the intensive care unit and being required to make a monumental decision:

And before I knew it I was in intensive care and I had been, I, uh, unconscious. I went into a coma apparently for about three days and then I woke up and in that, it would be afternoon I believe, they came to me and said you need to be on a ventilator. You are not going to improve. It's gone too far. And they didn't give me a choice really. They said, either that or you have, we can't tell you how long you'll live (Margaret, 33-44).

Such a decision came as a great shock to both Margaret and her husband:

I was shocked, yes, I think we were both shocked. My husband and myself were both shocked. I mean what do you mean she's going to go on the ventilator? What's in a ventilator? I don't know what. You know we had no clue (Margaret, 108-111).

Margaret felt somewhat lost in the language of intensive care, and the endotracheal tube prevented her from speaking:

I couldn't even talk at that time because I was intubated so I was nodding yes and no kind of a thing. And I didn't even know, um, like intubation. I didn't even know what that meant or anything like that (Margaret, 239-243).

During our interview, Margaret became very emotional when she recalled that she really had had no choice, given her circumstances. She recognized that her very life had been in peril:

And I said, well there's no choice. I'm not ready to go so, you know, yea. (Margaret, 270; 274).

Her time in ICU was initially "fuzzy", "because of not being with the world kind of thing" (Margaret, 317-318). When Margaret became more aware of her surroundings, communication challenges arose:

And even in the simplest things like I need another blanket or something or I wanted (my husband) to bring something home from our home or something. I, I just found it very frustrating (Margaret, 381-384).

A one-way valve was installed in the ventilator circuit, in order to facilitate the movement of air over the larynx and improve the ability to communicate. More concerning for Margaret was "finding the right trach tube" and learning how to eat and swallow on the ventilator. She was determined to learn, as the stakes were very high:

Because that was the hardest part for me the eating and drinking but other than that I mean I think everything else was going to fall into place . . . I think it was because I had to do it. If I didn't . . . well you know (Margaret, 927-931).

Margaret related that being on the mechanical ventilator served to, very quickly, alleviate the debilitating CRF symptoms. It was as if a huge fog had been lifted from her brain and Margaret was then able to reclaim a self that had previously been subsumed within the symptoms of CRF:

I think I was better within 48 hours of being on a ventilator. My headaches were disappearing. I was getting my, my ability you know, my strength was getting better. And I seemed to be, I think I was brighter than, than usual, you know, than I had been in years (Margaret, 665-670).

Despite feeling better, Margaret spent many months in the ICU and in the hospital and she became frustrated by the delays that were preventing her from getting home. Her husband articulated their frustration:

So the biggest part of Margaret's stay in the hospital was waiting to get the equipment put onto the wheelchair. That was the part that took the longest. Yea. So that was the longest time. Just basically waiting to get the chair fixed (Bob/Margaret, 469-471; 499- 500)

Over the course of five months, Margaret's horizons were very limited:

Because I couldn't go anywhere. I mean, you know, I was hooked up to the ventilator which was sitting on my night table and that was as far as it went (Margaret, 522-524).

For six weeks there was an intense focus on learning about the ventilator:

We had to learn how to do trach dressings. We had to learn how to put the circuits together. We had to learn what alarms meant and everything else (Margaret, 549-551).

Eventually there was a discussion about living arrangements, and health care professionals assumed that Margaret would be going to live in a long-term care facility.

Margaret had other ideas:

Nursing home, Oh yea that was the biggest thing. You're going into a nursing home where you could be monitored. I said, no I'm not. No way Jose. And, you know, I was just adamant. I was not going anywhere else but my home. I was not moving. I had to put my name down for a nursing home. I'm not doing it. No. I'm going home (Margaret, 566-570; 587-588).

Margaret related that she was "very hard-nosed when it comes to something like that" (Margaret, 635-636).

And the nurses and the doctors felt very, you know. I was bucking heads on that kind of thing and I told them I'm not going into nursing (home). There's no need for me to go into a nursing home, you know (Margaret, 647-650).

Margaret made a case for herself and her self-advocacy efforts were eventually rewarded:

Once you get the nurses and doctors on your thinking level of independence, you know, they're for it. I mean they see that what makes a person happy is to be independent and I think that's what I've got, you know, that's what I've, through all this I think that's what, I think that's what they understand now is Margaret wants to be independent and this is what she's going to get, you know (Margaret, 1524-1532).

She felt well prepared to return home:

Yeah. Because they'd always ask questions like, well what do you do if this happens? Or what do you do when that happens. Well, my husband's right there. I mean he bounced in and out you know, as quickly as he could (Margaret, 687-690).

Margaret went home for a few trial runs prior to returning there to stay. The first night at home Margaret and her husband were confronted with a particularly distressing challenge. The ventilator malfunctioned and every alarm light was on. Margaret and her husband successfully handled the situation and, as a result, their confidence grew:

And, Oh yea. My ventilator just conked out. Totally conked out. Totally. There was nothing we could do. So we said, OK, get out of bed, and go into your chair, dah, dah, da, dah, dah (Margaret, 763-766).

Margaret spoke of the psychological adjustment to being ventilated and how successfully dealing with past health challenges had assisted her with transition to ventilation:

Psychologically, I kind of, I kind of said, well, it's just one more hump I had to go through. I mean, of many I've gone through in my life. So this is just one more. And it's a little close but I made it. I've been doing it this long I can do it some more. And that's all. That's all I can say. I mean it's done, it's over with and I'm here. Yea, and that's the way I look at life I figure (Margaret, 844-851).

Margaret revealed her perspective on life since being ventilated:

Life has been really good. I mean I've, even though I don't work. I do a lot of volunteer work (947-948). But I wasn't tired because I wasn't getting the headaches. I wasn't doing this, I wasn't, you know, I felt really good. And very, you know it was like a new lease on my life kind of thing because I'm free again. I can do, I can go out there and I can actually do something, you know (Margaret, 1022-1027).

She described feeling a tremendous sense of service toward other ventilated persons. Her effort to assist others provides her with a great sense of personal satisfaction:

Yea, I'd wheel. Oh yea. I mean I'd drop anything to, to make somebody else feel at ease (Margaret, 496-1497).

Margaret reflected on her life prior to LTMV:

No, I don't see it as a bad thing because it, what I had before was nothing. I was nothing before then, you know . . . (Margaret, 1051-1053).

Summary-Beginning Interpretations

The stories of Margaret and Rose illustrate unique facets of the experience of transition to LTMV. Chief among these were the participant's age and stage of development when respiratory crisis occurred. What is similar; however, are many of the thematic elements of the lived experience. Both individuals describe a protracted, passive symptom experience, the significance of which was apparent in hindsight. The impact of the symptoms on their lives was similar in that their worlds had become increasingly narrow. The loss of the ability to be "self" was apparent through retrospection and was expressed in Margaret's words concerning life before mechanical ventilation, "*I was nothing, before then you know*".

Despite chronic motor disease and thoracic wall changes, neither Rose nor Margaret had ever been referred to a respiratory specialist. They both experienced a dramatic, life-threatening crisis that required intubation and ventilation. They became very aware that they were close to death, and as they undertook the physical work of adjusting to a tracheotomy and the ventilator, they struggled with psychological adjustment. They experienced a paradox of having renewed energy, while also

recognizing new restrictions on the way in which they were required to live their life.

They also experienced loss.

Margaret and Rose focused their energy on making a case for their independence, autonomy and their future; and they did so within the context of a prolonged hospitalization and a prevailing view that they should live in a LTC facility. Ultimately, they both returned to independent living and made the ongoing adjustment to living life on a ventilator. They gained perspective about life that was embedded within their experience of transition. Both Rose and Margaret expressed satisfaction with their lives.

Thematic Analysis

Transition to long term mechanical ventilation: The lived experience of individuals with chronic respiratory failure

The Essence: Sustaining the "Self"

The previous section presented two of the participants' stories, and provided a beginning interpretation of them. This section builds upon those beginning interpretations and presents a thematic analysis of the experiences of participants' transition to long-term mechanical ventilation (LTMV). In this section I will present narrative and parts of the stories of all ventilated participants in order to demonstrate the meanings that emerged from the data.

Elizabeth described her perception that people do not understand what it is like to experience respiratory failure, be confronted with death, and choose to be mechanically ventilated. She sensed that others believed it might be better to die. *"I suppose there's the old let nature take its course (theory). Until I got in this boat, I did not understand either"* (Elizabeth, 337-338).

The ventilated individuals in this study found themselves in the very same boat as Elizabeth; they experienced being close to death and they chose life, which meant embarking upon a journey that would take them through rough and, sometimes, uncharted waters. Eventually, the waters calmed; but it took time, persistence, hard work and patience to bring the boat to anchor. As mechanically ventilated participants reflected upon the rough waters that they had navigated, the meaning embedded in the living of their journey became clearer.

Transition from respiratory failure to the stable reliance upon LTMV involved movement through a trajectory of significant experiences including: symptom experience, crisis and struggle, and a time of renewal and a sense that life goes on. Underlying the transition journey was a tension between sustaining self and losing self. For the participants in this study, the overall essence of the lived experience of transition to long term mechanical ventilation is sustaining "self".

The experience of self is viewed in psychology as a cognitive, experiential phenomenon that involves a merging of the person's awareness of themselves as an object and as an actor in the social world (Markus & Wurf, 1987; McAdams, 2001). Participants living with CRF revealed that their capacity to "live self", through cognition and awareness, and as an actor in the social world had been profoundly compromised by the surreptitious, and mentally incapacitating symptom manifestation of CRF. 'Self' has also been conceptualized as identity, internalized through life story (McAdams, 2001). Through retrospection, VAI were able to fill in the life story that had been, more or less, subsumed within the symptom experience of CRF.

Most participants had lived with debilitating symptoms of CRF, ultimately experiencing acute respiratory crisis and a confrontation with death. Choosing not to die meant being mechanically ventilated and learning to breathe, communicate, eat and live in a different way. As ventilation was re-established, symptoms subsided, and cognition and awareness were restored. Yet participants found themselves constrained by new restrictions imposed by MV, and they struggled for their right to self-determination and autonomy.

Individuals revealed transition to be a process that was both physically and psychologically demanding and encompassed several events, all of which were significant in the overall meaning of their experience. Schumacher and Meleis (1994), describe transition as involving mental processes and the individual meanings that are attributed to events as they transpire. The following section will present five main themes that illuminate the mental processes, and the individual and shared meanings that describe the lived experience of transition to LTMV.

The themes that characterize the living of transition to LTMV are: (1) *Tyranny of symptoms*, (2) *Self in peril*, (3) *Awakening to a paradox*, (4) *Struggling for autonomy* and (5) *Life goes on with a reclaimed self*. Each of these themes has several sub-themes that together comprise the main theme. Table 5.1 provides an overview of the themes and sub-themes revealed through thematic analysis of the participants stories of their experience of transition to LTMV.

Table 5.1

Themes and Sub-themes of Sustaining Self: The Lived Experience of Transition to Long-term Mechanical Ventilation

THEME	SUB-THEME
Tyranny of symptoms	Experiencing symptoms <ul style="list-style-type: none"> • Second guessing reason for symptoms • Health professionals do not recognize impending crisis
Self in peril	I am close to death <ul style="list-style-type: none"> • Making a decision (having no choice) • Being in the intensive care unit • Being ventilated
Awakening to a Paradox	Renewed energy /// Restrictions <ul style="list-style-type: none"> • Experiencing loss
Struggling for autonomy	Making a case <ul style="list-style-type: none"> • Confronting operational, & bureaucratic challenges • Gaining new knowledge about the health system and living with technology <ul style="list-style-type: none"> ▪ Waiting
Life goes on with a reclaimed self	Recreating home <ul style="list-style-type: none"> • Mastering technology &-equipment • Gaining perspective • Living with uncertainty

Tyranny of symptoms

Tyranny of symptoms characterized what it meant to be passively, yet undeniably, incapacitated by the symptoms of chronic respiratory failure. Participants' symptom experience was remarkably similar: a gradual, insidious decline in the capacity to carry out activities of daily living, and a loss of energy to engage with people and the world. As individuals reflected upon their life at that time, they recognized that they had lost themselves. "Self" had become subsumed within the tyranny of the symptoms of CRF:

Life was just going by and there was no care in the world. The mind had basically shut down. Like there just didn't seem to be a care (Adam, 370-372).

My breathing (was) poor enough or I didn't do well enough in my business in my career because there was something wrong. . . All those years, and, uh, but it was always a lack. There was something lacking in my body and my being and that was enough oxygen. . . I felt incapable of putting up with the day's activities (Paul, 510-512; 697-699; 704-705).

And over time I just found it, I wasn't doing as much, or if I was doing it I was tiring much quicker (Meg, 40-42).

Embedded within the loss of self was the actual symptom experience, which included: 1) physical distress, 2) behavioural manifestations, and 3) a cognitive aspect. As individuals lived with the debilitating physical manifestations of their illness, including headache, memory loss, mental cloudiness, diminished state of alertness, tremor and shortness of breath, they adapted their life to a diminished energy level. Their world narrowed as their capacity for engagement became increasingly compromised. As symptoms were experienced, individuals thought about them; underestimating their significance, and pondering their origin or cause. Participants sometimes sought the help of health care professionals, but those efforts did not usually result in symptom relief or a better understanding of their cause.

Experiencing symptoms

Individuals reported shortness of breath, fatigue, loss of energy, personality changes, loss of memory and cognitive capacity, and a feeling of being groggy or drunk.

Physical distress was uncommon, with the exception of headache:

One night I went to lie in bed and I said I can't breathe on my back. And it was very strange. So from then I had to adjust how I slept and then the fatigue and, you know started. The tiredness and the struggling. The actual struggling to get air in and out, you know (Elizabeth, 226-231).

Mine was when I start to not remember, um, dates or appointments. Um, even if you had written them down, you'd have to go right back to the, to the book to look them up again. Any of the phone numbers that, um, you know off by heart. And I had roughly about a hundred phone numbers which were lost (Adam, 63-68).

In retrospect, participants recognized that symptoms had usually developed gradually and progressed over a very long period of time:

It's really hard to pinpoint because it was over a very long period of time; just very, very gradual. And it wasn't until (year) that I really started feeling so short of breath that I just had absolutely no energy. I was falling asleep during the day, which was totally out of character for me. I mean it was over probably a 20 year period (Meg, 17-21; 42-43).

Participants sometimes spoke of their body in a disembodied manner and the manifestation of symptoms as occurring separate from their "self". Paul often recalled the dialogue between his mind or brain, his psyche, and his "self". He seemed to describe a cognitive awareness of the cerebral manifestations of nocturnal hypercapnia:

They often wondered, you know, how can you do it? I don't know how to explain it. If there is such a thing as a brain nausea, my brain was suffering from a nausea and then it would just not let me sleep. It would wake me up. Now why am I awake? Well I knew I had to replenish my body with oxygen. And the way to do it is to do it artificially. Sitting up at the side of the bed and pumping, and I've done, I did it for 15 years (Paul, 331-332; 357-364).

Yes, I developed, that brain told me that, you know, you feel, I don't know how to put it, but your head feels heavy, you know, it doesn't feel normal. And you can't cure it with aspirins you find out. I had headaches. Energy was diminishing you know with this (Paul, 647-649).

Adam also talked of “the mind” as being an entity separate from his “self”. He had become aware of the fluctuating capacity of his mind:

But because then I could, the mind being more clear, I could self direct plus . . . (Adam, 934-935)

Frequently the meaning and significance of symptoms went unrecognized; rather individuals believed that there must be a benign reason for them:

Well I think at my retirement, I was kind of all worn out already (Annette, 13-14).

At some level I probably did know that something was wrong with my breathing but I, I kept attributing it to being tired, you know (Rose, 40-41).

Towards the end I did have morning headaches that would disappear an hour after you were up. Looking back, absolute symptoms. At the time . . . oh I slept crooked on my neck or, you know, you'd sort of find some reason why they were happening. And should have done something about it I suppose at that time but hindsight being 20-20, of course you didn't (Meg, 52-58).

Often it was the friends, family and other people, close to the individual with CRF, who became alarmed by the symptoms they observed:

It wasn't my choice. It was my husband's choice. He came home from work and just said, you know, like enough is enough. I'm taking you into hospital. You can't do anything. And, you know, you're having trouble breathing. It's ongoing for long enough. It's time we did something (Meg, 106-110).

Participants repeatedly revealed that those health care professionals who were consulted about symptoms did not seem to recognize the gravity of them. Diagnostic study, consultation and intervention were often delayed or neglected. It was clear that most participants were not aware that their primary disease conferred a risk for respiratory failure:

This ventilator problem came quite out of the blue for me (Margaret, 82-83).

Thinking I should do something about it. But not really knowing where or what to do about it and I just couldn't do anything without feeling totally exerted. And at

that point I did. I went to the doctor and he said if it gets any worse, get to the hospital. And it was that weekend that I went to the hospital (Meg, 45-46; 21-26).

Both Faith and her husband indicate that the potential for breathing problems had not been discussed by the neurologist and that they had not seen any signs of breathing problems prior to an arrest episode in physiotherapy. Faith had just been "very tired" (Field notes, Faith/Mark, 39).

Self in Peril

During one interview, a participant became very emotional when she began to speak of her experience in the hospital. She had been taken aback by the extent of her emotional response. When she regained composure, she wished to continue with the interview; however, following the interview she spoke of what it had been like to experience "the grim reaper" so closely. She explained that it was something that she had put out of her mind, yet when she reflected on that time, she had been shaken by the memory of being so very close to death.

Recognition of being close to death characterized what it meant for participants to experience a crisis and to then be required to make a decision about their future. Nine participants experienced a physiological crisis, when their body was no longer capable of compensating for chronic ventilatory failure. At that point, their condition was unequivocally life threatening and emergent ventilation was required. Sometimes the initial assistance came in the form of non-invasive ventilation, most often a BIPAP or CPAP system. At other times, participants were immediately intubated and ventilated. In all cases, communication was impaired because of an altered mental state and/or the inability to articulate as a result of being intubated or requiring a mask.

Making a decision

Individuals were often asked to make a decision about their future, which heightened their awareness that life was indeed, in peril; it put a name to what was

happening to them. Linked to making a decision was the notion of choice. Frequently participants reported having had no choice. It became clear; however, that what participants meant by having “no choice” was that they had only two options, ventilation or death, and no participant wished to die:

. . . They just took me in and they said they had absolutely no choice as to what to do with this human being who has this respiratory problem and did have a lack of oxygen. There's just one option we have left. And that is giving a tracheostomy . . . And I had to sign the paper that they could do that. And at that time, of course, I was desperate. I had to have something done. I knew that. And so I signed for it (Paul, 731-740).

With the other conditions that have crept into my life. Knowing that not being put on the ventilator, that life would have been over because life, or the condition, was heading that way in a hurry (Adam, 573-576).

And I was, while I was here and this occurred it kind of made me think, good God, am I that close to death, you know, like I was kind of leery there for a little while (Molly, 486-489).

And he says Jackie you're going to have to have the respirator or you'll die (Jackie, 446-447)

Faith felt as though she did not have a choice and that she just had to accept being on a ventilator, because Faith did not wish to die (Field notes, Faith/Mark, 54).

He says you don't (have any time). We're going to have to do it (the tracheotomy). It must be done now and it just took off from there (Meg, 116-118).

For two of the eleven participants, ventilation commenced on an elective basis, as a result those participants conveyed a greater sense of preparation and choice, although they did sense their nearness to death and they were fearful at the time:

I always said at the first, well at least I'm breathing. But then that soon became a not so funny thing as my breathing started to go. Um, yea, I think that was a scarier part than losing my muscle functions because when you can't breathe, you know, that's pretty well, unless you get assistance . . . So I found it, uh, I don't know if the word, I guess frightening to a point (Elizabeth, 63-70).

But knowing that if it actually came to having it, I would probably go on it but with a lot of reservations about having to. There was some reservations about first going on it (Adam, 519-521; 529-530).

Elizabeth used BIPAP prior to invasive ventilation:

(I was) using the thing whether I liked it or not. I was going to use this Bipap because it was a way of making myself continue to live and feel better. So I think my attitude along with the staff's encouraging attitude worked well together on the whole Bipap issue. I used it the first night for several hours and from then on it was my friend (Elizabeth, 387-394).

Forward planning did not eliminate uncertainty. Elizabeth explained that there had been a lot of confusion. Though she was desperately searching for firm footing, far too often it seemed as though the rug was being pulled out from under her feet:

Well it was a little frightening because, well part of the thing was care, you know, I'd been informed again of people that I knew that were on trachs or the people I had corresponded with were very reassuring that there's no way you had to have actual nursing level care for suctioning and things like that, that happened when you're on a trach. But, my professional people were still telling me that you know, I would need this and I would need that and it would be impossible almost to get it all arranged. And so I was still a little more worried about the practical aspects than the physical ones on me. I was more concerned about how we were going to manage at home and whether I could talk anymore and/or eat. (Elizabeth, 459-479)

Entrenched within all participants subsequent experience with transition and ventilation was the profound experience of 'self' in peril.

Being in the ICU

The necessity for mechanical ventilation meant that individuals found themselves on the ventilator in the intensive care unit, where they survived in a world of intervention and adjustment. Participants recalled their initial experience of having a tracheotomy, being ventilated, and of having difficulties communicating while they were in the ICU.

Elise recalled a sense of fear and angst. She questioned why?

Well I think because everything happened so fast, all I could think of was well what did I do that this happened to me. Which, of course, I didn't do anything. But it's hard to grasp. And I was scared of the whole business (Elise, 242-247).

Several participants who had utilized non-invasive ventilation prior to

tracheotomy, described feeling confined or claustrophobic with the mask on their face:

Um, I know it was supposed to help me breathe but I almost felt suffocated. It's kind of a weird feeling because you know it's there to help you breathe but at the same time it's almost like someone's holding something down over your nose and mouth so you can't breath (Meg, 223-227).

I remember having the face mask and I do remember being frustrated with it; frustrated that I couldn't speak. I remember lifting it off my mouth every time I wanted to talk. Getting heck for it (Meg, 199-202).

When Molly spoke of her experience with a BIPAP system, she physically pushed on her face to indicate pressure and discomfort. By contrast, she indicated that the tracheotomy, together with mechanical ventilation, provided her with relief:

I mean at that point anything was better than a BIPAP (Molly, 170-171).

Having a tracheotomy was a particularly difficult experience for Rose, who was a very young woman at the time of the procedure:

I couldn't even look at it actually for the first six months. I couldn't look at it period. I refused to touch it. I wouldn't do the care. They had to do the care. I didn't want to (Rose, 509-511).

Paul had seen other people with a tracheotomy; however, that did not help him understand how it felt to be the one with the tracheotomy:

It was an uncomfortable object in my throat which I didn't know what it was but I had seen people with tracheotomies of course. Looking at something is one thing, experiencing it is another (Paul, 793-796).

Being ventilated

The actual process of breathing on the ventilator provided some individuals with a sense of relief:

It was a very, very strange sensation to be told not to attempt to breathe on my own, to let the machine do the work for me. But it didn't take very long to realize, hey, this was kind of good. I've got nice big breaths happening and going in and out and I really didn't find it too hard to adapt to (Elizabeth, 531-537).

Hm. I don't have any feeling of sensation (on the ventilator). It's just that, going to bed at night and sleeping. And I love to sleep. Not a bit of trouble getting used to the ventilator. I was glad. Like I didn't know whether I was breathing. But I was breathing (Molly, 178-179; 213; 277-278).

I expected it to do what they said it would do. And that is to improve the respiratory system's function. And it does that (Paul, 1047-1049).

For others, breathing on a ventilator was a significant challenge:

The machine would be breathing in and I was breathing out. You know I couldn't coordinate myself with the machine. I was always breathing against it. I had lots of problems with that. I couldn't get used to it (Jackie, 525-537).

Jackie recalled the nurses telling her just to breathe with the machine, which was not such an easy thing to do:

But you can't and you don't know how and you're gasping for air and you're gulping air in your tummy and you get bloated (Jackie, 1154-1155).

You're getting two airs instead of one so that's not very comforting. Eventually I got used to it. It took me a while (Jackie, 1077-1078; 555-556).

While in the ICU, participants occasionally required suctioning, an intervention necessary to remove secretions in order to keep their artificial airway patent:

The suctioning was the worst. I hate it. Like they're putting a hose down your throat. And sometimes they don't get it right in the middle and it goes to the side. And it pokes you instead (Jackie, 567-572).

Virtually every participant spoke of the communication challenges that occurred while they were in ICU on the ventilator. Their compromised ability to communicate resulted in feelings of frustration, dependence, vulnerability, and isolation:

It was very frustrating. For them as well as for me. You know I understand they were just as frustrated. He was the worst. My husband was the worst. Kids could kinda, you know, would understand a little bit of what you were saying. And I

spent oodles of paper, lots of time writing on paper to try and get them to understand what I was trying to get across (Meg, 284-288; 328-330).

Most (difficult) thing was not being able to speak right away (Elizabeth, 537-538).

I had to write everything down. Well to me it was very difficult because it's; I couldn't even drink water or anything. So I always had to ask for somebody to attend. And that isn't too pleasant (Annette, 225-226; 466-468).

Basically I was scared because I didn't know if people would ever hear me or know if I was having problems or whatever, but they, uh, they had, um, trying to think what they hooked up (Elise, 133-135).

Awakening to a Paradox

As pulmonary ventilation was restored by technology, carbon dioxide levels fell, oxygen levels rose and participants experienced renewed energy:

Once I went on Bipap I felt I could breathe. It was very, very nice. Very, very nice sounds kind of corny I guess, but it was because it pushed that air in and got my air out and I felt I wasn't struggling and right away I discovered I could talk with it on. I was thankful for it because it really made me feel better right away (Elizabeth, 400-408).

Awakening to a paradox characterized what it meant to experience renewed energy or vigour, concurrent with new restrictions that limited what one was able to do. With increasing energy and an improved mental status, participants began to reflect upon what they had been through, where they were and what it all meant for them:

Well I think because everything happened so fast, all I could think of was well what did I do that this happened to me. Which, of course, I didn't do anything. But it's hard to grasp. And I was scared of the whole business (Elise, 242-245).

Physically, my body adjusted really easy. It was more the emotional, emotionally and psychologically was harder to get used to, knowing that it was going to be with me for the rest of my life. Even though they had already mentioned at the time that it was probably within 1 to 2 years, I was going to have to be on it 24/7. And knowing that that was not what I wanted, just knowing that there's more restrictions put on what you can and cannot do. And that's not what I wanted (Adam, 477-486).

Many participants revealed a sense of loss: loss of freedom and independence, and loss of their prior way of being:

Loss of relationship occurred . . . Because of something that I physically, I could not control. I had no control over ending up on a respirator, you know. It was a reality that I had to deal with. And, uh, unfortunately that reality requires a person to be pretty brave. The partner. Right? And, you know, we were young (Rose, 561-566).

Jackie feared that being ventilated would mean that she would lose being with her mother and living at home. When her mother learns of this, she responds that she absolutely wants Jackie to live at home. Jackie remembers telling her mother:

I just thought the machine would scare you and I didn't want to go home and give you all of the responsibility (Jackie, 467-469).

Renewed energy/Restrictions

Being on mechanical ventilation resulted in a number of constraints or restrictions upon the way participants lived their lives. Restrictions were often imposed by health care providers, who communicated and demonstrated their need to maintain close proximity to the VAI. Adherence to hospital-related policy was another concern raised by HCP. However, the most conspicuous restriction was the ventilated individual's omnipresent physical connection to the ventilator, together with its requirement for access to an electrical source or a charged battery:

It just feels like I'm not as free anymore. I didn't feel as free as I was before. I didn't like the hose around my neck (Jackie, 506, 511,453).

Well the thing is I'm not free. Because this is, that's the first thing you have to attend to (Annette, 857-858).

So if I was going to go somewhere I really had to work around when I could use the Bipap or take it with me and plug it in somewhere or whatever (Elizabeth, 444-447).

Mobility, which had been a prior concern for many participants, became a more complicated one, as many wheelchairs needed to be modified in order to support a ventilator and this often took a good deal of time:

Because I couldn't go anywhere. I mean, you know, I was hooked up to the ventilator which was sitting on my night table and that was as far as it went (Margaret, 522-524).

And it was really frustrating because I brought the wheelchair down to the, down to the hospital of course. It's sitting in the room empty, not being used, while Margaret is, you know, on the vent on the nightstand by her bed. And just having the chair there and not being able to use it, and waiting and waiting and waiting (Bob/Margaret 507-514).

In addition, being ventilated in the hospital imposed other constraints that arose from concern that something might go wrong with the machine. Participants became aware that HCP knowledge of the technology upon which they relied was not "standard", thus they were cognizant that they, and their ventilator, could only be situated in a few units within the hospital:

It was quite an undertaking because they didn't have a respiratory patient for, oh a good 10 years. So they had to learn everything over again too (Elise, 281-284).

Finally, participants became aware that life on a ventilator, in the hospital, was a life that was monitored because health care professionals had ongoing concerns about safety:

You're going into a nursing home where you could be monitored (Margaret, 587).

As participants continued to experience the restrictions imposed by mechanical ventilation, they spoke of a changing sense of freedom, independence and a "self" that was, once again, in jeopardy:

Well to me it was very difficult because it's; I couldn't even drink water or anything. So I always had to ask for somebody to attend. And that isn't too pleasant (Annette, 466-468).

They gave me some kind of a little tubing inside. And I was miserable . . . It was just like a little plastic spring, you know, like a coil, you know. And in order for me to speak then, I didn't have to write it down, but I had to ask them to release it. . . . And if I wanted to eat, I had to have them undo it also (Annette, 382-383, 387-389, 394-395).

It wasn't that I minded the amount of care; it was just the thought of the restrictions. You had to think more before you went out. And that part bothered me. And so with that, it was, um, it was one of the main things of not wanting to be on it (Adam, 510-515).

Paul had experienced prior adjustments to ventilator technology over the course of his adult life. He related that with each technological change, came a corresponding loss of freedom. He spoke of his rocking bed:

But now I was again fighting. You have to stay at home. You can't go on holidays. You can't take a family with you because this rocking bed is a big metal heavy thing that had to stay at home (Paul, 556-561).

Ingenuity, innovation, and family support helped Paul to maintain a sense of freedom.

Struggling for Autonomy

Having become aware of their nearness to death, and in the wake of being liberated from the symptoms of CRF participants were, once again, confronted with a threat to "self". Participants struggled for their autonomy, and this was manifest in their efforts to make a case to health professionals and the health system. Embedded within each participant's case was that which they wanted most: the opportunity to determine how their future might unfold. One participant described her desire to live independently, stating that she was:

Willing to go to the ends of the earth to do whatever she had to do in order to get it (Rose, 824-825).

Making a case

The struggle for self-determination was manifest in self-advocacy:

And, you know, I was just adamant. I was not going anywhere else but my home (Margaret, 568-570).

Not long after Elizabeth learned she was living with a progressive neurodegenerative disease, she began to make a case to HCP as she had decided that she wished to be ventilated. Elizabeth learned very early in her transition experience that she would need to advocate for herself and she was very grateful for her skill in that area:

I was going to have to fight for what I wanted in order to get ventilated and go home (Elizabeth, 295-296).

I was really glad I'd never been a person that felt I couldn't talk to a doctor because he was, uh, royal highness of whatever. I always, you know, I always felt that I could sit and talk whatever my needs were, and it definitely helped me all through this because I think if you are of the old school, per se, that you would really have had a struggle because everything that was presented to me was against what I was thinking I would want (Elizabeth, 310-318).

Participants experienced conflict between themselves and their care providers. For participants, it seemed that health care providers were most concerned that something might go wrong with the ventilator and that the ventilator user would be without adequate assistance:

Nursing home, Oh yeah that was the biggest thing. You're going into a nursing home where you could be monitored. I said, no I'm not. No way Jose. And so (Margaret, 566-567).

And the nurses and the doctors felt very, you know. I was bucking heads on that kind of thing and I told them I'm not going into a nursing. There's no need for me to go into a nursing home, you know (Margaret, 647-650).

The length of time spent in the hospital became meaningful for participants in the sense that they struggled to maintain their identity within the sometimes oppressive hospital culture. Individuals began to feel as though they were waiting with their lives on hold. They shared a belief that they were being required to stay in the hospital for too long:

They made me stay in there six weeks. And I would have been out way before that time but they wanted to be sure we were all, and I understood that, and I finally said, no, this is long enough. I'm ready to go home (Elizabeth, 632-636).

I remember wanting to go home. Um, I think, was hard because I wasn't sick and yet I needed the ventilator. And that was the only place they had it. And, a little frustrating in that you couldn't do a lot of things that you probably should have been able to do if you'd had, you know, even a ventilator at home that you could have. You know where they could have taught you in time. Which was what eventually happened. I would have liked to see that happen sooner. I think. Like I was in the hospital I think three months. And probably after a month and a half maybe, 2 months at the most, I probably could have been home had I had the opportunity to get into the program sooner. Because I think it was only three months after I started the program and then I was home (Meg, 391-404).

Participants confronted operational and bureaucratic barriers:

So finally the process got started and my coordinator said, you know, just because it's in the works doesn't mean you're going to be accepted. And I thought, Oh well this is great. Here I am on the trach and wanting to go home and pretty sure that we'd be able to get home. But, you know, blah, blah, blah. Any way so (a HCP) phoned and they are still totally afraid of people at home and ventilated with ventilators. They're really not totally knowledgeable (Elizabeth, 662-666; 650-653).

As Elizabeth struggled to return home, she spoke of her sense that it had been important for homecare providers to actually see and speak with her. She described the possibility that stigma occurred along with a lack of knowledge and understanding:

And then they'd have more understanding what was going on. And then they'd come in and talk to me. Holy jeez, you know, she's talking and she's whatever and she's doing and she can speak her own mind and can whatever. And think they were kind of just, I don't know, they expected a feeble little person in the corner on her little ventilator and, you know. And so they agreed to move as fast as they could (Elizabeth, 666-675).

Paul spoke of his resolve to return home:

My home is my hospital you know, that's always been after polio. So I expect the resolves that need to be dealt with can be dealt with here. They can probably invent in hospitals and they can do what they can do. But care and maintenance that you'd better teach me how and I'll cope with it at home. And I need help for that. And I have home care workers now (Paul, 1035-1040).

When participants were successful in making a case they experienced a sense of satisfaction that they had helped the health care professionals to know them. For several participants, it was only then that they developed a sense of partnership with the health care team:

Once you get the nurses and doctors on your thinking level of independence, you know, they're for it. I mean, you know, they see that what makes a person happy is to be independent. and I think that's what I've got, you know, that's what I've, through all this I think that's what, I think that's what they understand now is Margaret wants to be independent and this is what she's going to get, you know (Margaret, 1524-1532).

Life Goes on with a Reclaimed Self

For those ventilator users who had successfully made a case, the focus, once again was on moving forward. For ventilated individuals in this study, life did go on; however, life was not as it had been prior to transition to MV. While the ventilator literally sustained life, and VAI were profoundly aware of having been close to death, it was not their biological existence that had been in transition. Rather, the work of the ventilator had renewed the self that had been subsumed within the narrowing world of CRF symptoms. It was a renewed self that grieved significant loss, developed new knowledge and skill, and advocated for a life envisioned.

“Life goes on” characterized what it meant for individuals to reclaim their cognitive capacity and energy, and re-establish themselves as autonomous beings, despite their new reliance upon mechanical ventilation. Rose recalled that her overwhelming desire was to “*get back on track in what I felt was my life, you know*” (Rose, 1241-1242).

After a long hospitalization, it became very important for ventilated participants to recreate a home for themselves and their families. To do this, they needed to develop a sense of mastery of the “machine” that was their ventilator. Embedded within the

perspective of life going on was: frustration in a health and social system that sometimes sought to control them, pride in their courage to confront barriers and restrictions, and hope and uncertainty regarding the future.

Many participants returned to the home that they had occupied prior to their crisis event, while others were resituated in a long-term care facility (LTC). In either case, the overwhelming focus was on recreating a home in which they could be themselves and also “be family”:

I'm definitely happier at home. I've got my own surroundings. I've got, you know, we've had to make adaptations to the house and stuff but I'm here. I've got my own neighbourhood. I've got my pets. It's just a far better quality of life than I think you'd have in the hospital. No, don't get me wrong. I think one can still have quality of life in a hospital or in a home care or a nursing home or whatever. But it's not the same as at home. At home is home (Elizabeth, 723-726; 728-733).

Rose, who had spent years in the hospital, spoke about finally going home:

I was so excited. I mean I had to get the heck out of there, just get on with things. But at the same time I felt like I was leaving, leaving my family for the first time. I left with a sense that I was respected and I was on my own. And they were letting me go and wanting good things for me (Rose, 1101-1104; 1118-1120).

Elise spoke about what it meant for her to be home:

Basic interaction like especially in the summertime, we'll be sitting out here and people will walk by and they'll stop and talk. And there's more community involvement that way. And in the wintertime, we're always in the sunroom. There's people go by and we wave. . . (Elise, 563-568).

She spoke of being with her child:

We can play tea party and she plays dress up and we play board games and I have a TV screen that's used for a monitor for the computer. So she can be on one and I can watch her and even if she just sits there and I watch her play, I think that means a lot (Elise, 695-699).

For participants residing in a LTC facility, the journey to recreate a home was a very difficult one. The tension between losing “self” and sustaining “self” was heightened:

Going from home to a long term care facility, [pause] it is a loss. You lose part of your freedom and your space and being able to do what you want to do when you want to do it (Adam, 1012-1017).

Even here there's been a few nurses and aides that have, it's do it their way or no way. And going from independent living and being told that they would listen to, knowing that I'd come from living independently, and still had my mind, and then literally having stuff forced upon you or heaped upon you didn't sit very well (Adam, 905-911).

Molly's description of her life in a LTC facility mirrored Adam's in a number of ways, yet her experience was entirely different as she perceived her loss of independence in a positive light:

But, they told me what it was like here. And they didn't describe how good it really is. I mean I would---if they told me tomorrow that I'm cured, that I can go home, I would fight like crazy. I mean, I have, and I get care that's unbelievable. There's nothing different in my life whatsoever. I mean I can do what I want to do. In fact I'm, I feel, like they bathe me, they change my bed, there's nothing. I mean the nurses are full time here. You're treated like a child, you know, like they do this for you, they do that for me. Put your shoes on. Do my laundry. Hang it up. I mean I never had that when I was in perfect health or in health (Molly, 264-268; 410-416).

It was apparent that there were significant mediating factors at play. Molly's prior lifestyle had been relatively unchanged when she moved into LTC. She continued to have significant social support and she did not require her ventilator during the day, which facilitated her mobility.

Although participants in LTC made the journey to recreate home, it became clear that the experience of moving to and residing in a LTC facility was imbued with a lingering and sometimes visceral sense of loss.

When completing the demographic portion of the interview, Faith began to cry at the question about "home". It seemed to be apparent that leaving home had been a devastating loss for Faith and one that she continued to grieve.

Annette spoke often about her home, although she had resolved that she would never be returning there, she continued to imagine how life might have been:

Well it would be nice to stay home. Because I have all the conveniences. I have my, I have a hospital bed. I have a walk-in shower. . . . You name it, I got it. If they had people to look after me, they have a senior home and they have a hospital, like they do have everything (else). They need to have more trained help (in rural area) (Annette, 908; 948-950; 1068-1069):

Participants spoke of factors that helped them to adjust to life in LTC. Jackie felt as though her world had fallen apart when she moved to LTC. She continued to grieve the loss of her home; however, she felt that she was able to adjust to life in long-term care primarily because her family had made a significant effort to visit her and to include her in important events. Jackie disclosed that her main fear about moving to LTC had been that she would no longer be a part of her family. But, for Jackie, that was not the case.

Adam described the importance of having one's own belongings in order to begin to recreate a home. He also found meaning in preparing and tending his pot of flowers:

Having to give up my apartment and go to a nursing home, that part was harder emotionally to give up and adjust to (than being ventilated). But once I got here and got some of my stuff that had been put in storage, into my room, it helped (Adam, 881-886).

Mastering technology and equipment

For the ventilated participant and their family, the ability to master the ventilator and manage the tracheotomy tube, and other aspects of technology, figured prominently in their adjustment to life on a ventilator. In retrospect, some participants believed that they had been a little naïve when it came to their initial understanding of the ventilator. Inevitably, all participants were required to deal with a malfunctioning ventilator, or troubleshoot a problem with the tracheotomy tube or other equipment. It was the experience of successfully dealing with problems, and establishing a routine, that

ultimately provided the ventilator user with a sense of control or mastery over their machine.

Adam described the frustration that occurred during his adjustment to being home on LTMV:

If I had a baseball bat I probably would have beat the machine to death (792-793).

My wife, you know, helped with the troubleshooting, especially when the alarms wouldn't shut up. She would get up to help track down the problem, you know, in case there was, you know, a loose hose or stuff to help. And so it was generally both of us, but quite often it was myself you know. Quite often knowing that it was the exhalation valve (Adam, 722-728).

Meg described adjustment as a process that occurred over time and developed as one experienced success:

When I first, you know, they told me, OK, you're going to be suctioning yourself, doing your own trach it was just one of those things that's so foreign to me, there's no way. But it's surprising how quickly it doesn't; it sort of becomes second nature. The first time I tried to put the catheter down my trach to suction it was kind of an eerie feeling but, you know, once you do it and it works, the next time's not quite so bad. The third time, you know you're hardly thinking about it at all. So it isn't really as bad as it sounds initially. And it was the same with learning to change the trach (Meg, 762-773).

By the time I came home you didn't even really think about it. It was part of the package as you came home. Like you come home from the hospital with a new baby. It's a complete change. But, you know what, you deal with it. Now you have the diapers, now you have feedings, now you have bathing. All these things you didn't have before. Well it's sort of the same thing . . . I felt confident when I came home, for the most part, that I could handle everything (Meg, 1033-1046).

It continued to be important for participants to perform all of their care as independently as possible. Adam described self care and the importance of being independent:

I do all my own ventilator care including changing my own trach as well as doing my own suctioning and trach care and stuff like that which a lot of other people can't do. Which a lot of nurses are surprised that I can do including, changing the trach. Its more the independence and not having to rely on other

people to do it for me, which is something that I didn't have to give up, even though I wound up going (to LTC)(Adam, 581-586;590-593) .

For some ventilator users, the ability to be independent was predicated on the successful integration of attendants to assist with care. Although Elizabeth's non-verbal communication indicated that she missed the capacity and knowledge of her own hands, she spoke of her attendants:

You know they fit right in. I have the same ones I started with. And, uh, we all kind of get along fairly well. We've gone on all sorts of field trips and out to places and to do things and I, it's much the same old me with my hands working through them. They try to be my hands (Elizabeth, 742-747)

Attitude/gaining perspective

As participants reflected on the whole of their experience, they recognized that the transition to LTMV had been an unquestionably challenging process. They described what had been most difficult about their experience and what had made it all worthwhile. These were highly personal reflections, steeped in both suffering and triumph. Through introspection, individuals were able to share narrative insights that characterized what it meant to be able to go on with a renewed self.

Elizabeth spoke of transition to LTMV as an opportunity that had enabled her to be her "old self again". Her perspective was instilled with her past memory of losing self within the tyranny of symptoms of CRF:

It's a life altering transition for me, but a positive life altering transition in that I can be me again right now. You know, I, take this whole disease day to day. But for now and for over a year now, it has enabled me to be back to my old self again as far as my physical abilities will let me be. It makes me have to need 24/7 care (but) it gives me far more ability than I'd had for a long time to be me. Because I can go anywhere and do anything within reason. I'm a little frightened about going swimming with my ventilator. Hah, hah (Elizabeth, 754-764).

Just as Elizabeth had accepted the presence of an attendant as a necessary part of being ventilated, Meg and Molly also recognized the limitations and benefits of mechanical ventilation:

Yes, I have limitations but I think I'm able to have a normal relationship or life, you know, sort of thing. I don't feel that I'm missing out on anything because of having to be on the ventilator or oxygen. You deal with it. It (the ventilator) makes me feel a whole lot better because I know that overnight I am being ventilated. I don't have the worry of what if, what if. Because obviously after the episode in the hospital I know now that the headaches I had, the symptoms that were there should have been addressed. And now I know that isn't a problem. I don't worry. I know I'm being well ventilated overnight. What's the alternative, you know, so it doesn't really . . . to me it's not negative (Meg, 675-679; 694-702).

I just accepted it, that's the way life is. You can't fight what you can't fix. I mean there's nothing in the world that I can do to get off this machine so why fight it. I'm enjoying it and that's it. Well I look at it this way. There's nothing in God's earth I can do to correct my health other than this vent to keep me alive. And I don't even think of it as something different. Some people take sleeping tablets to sleep. And you just have to plug me in and I'm gone (laughs) (Molly, 423-424; 461-463; 429-433).

Meg talked about adjustment within the context of her past successes in managing health transitions:

It just becomes a part of who you are. And I think maybe having had the brace, you know, having to make the adjustment early on, it was just another one of those things that you sort of have to deal with (Meg, 612-615).

Paul's adult life was interwoven with his experience of respiratory deficit, to the extent that he had become very conscious of the biological functioning of his lungs. He actively avoided invasive ventilation for many years by incorporating non-invasive ventilation devices and behavioural adaptations into his life. Paul's words reveal an ongoing dialogue between his "self or psyche" and his bodily respiratory function. His biological deficit resulted in a heightened awareness of that which makes him human: his soul:

Convince yourself that you have the ability to deal with this problem and the issues are very often just that.

It's a matter of my reaction to what my body tells me and what my mind tells me you can or cannot cope with this, you know?

And I was always, I always have been of the idea that, that's in one's control, you know, and then the physical will give into it very quickly. Your psyche is there to remind you, you know, that you are not just a body, you are a body and a soul (Paul, 1067-1075).

Paul experienced a crisis and he eventually succumbed to his physiological need for invasive ventilation. He reflected on the years that he had struggled with the symptoms of chronic respiratory failure:

After years, after a few decades, you find out that the, it would have been probably a better idea to cope with it (invasive ventilation) in the last 40 years rather than just in the last 3 years or 4 years (Paul, 1315-1318).

Paul disclosed that one of the reasons he had delayed using the invasive system was his concern related to body image or aesthetics:

I look nicer without it than with it .Cosmetics play a big role in people's lives (Paul, 1289-1295).

He also described his drive to prove himself to others.

I was out there to prove to this world, you know, this guy can have a lot of disabilities but he also has a lot of abilities (Paul, 1336-1338)

Paul also avoided invasive ventilation because he understood, early in the course of CRF, that a mechanical ventilator would mean more technology to cope with.

There was a mechanical need that would exist that does not exist if I don't have it (Paul, 1300-1301).

Elise revealed that she had thought about choosing to die:

And, just I had family that, I mean, I have to see my nieces and nephews grow up. I couldn't just you know, expire. And then they would wonder why . . . I think in the long run it was a learning experience for the kids (Elise, 776-778; 785).

You come to the realization that unless there's some, some kind of, um, new technology that's come out, that you have to just work with what you have. There are still times that I have down days of course. That's only natural. But I think I've adjusted OK (Elise, 933-935;971-972).

For Margaret, "life is good". As with other participants, her perspective is entrenched within her memories of her past struggle and her loss of self:

No, I don't see it (the ventilator) as a bad thing because it, what I had before was nothing. I was nothing before then, you know (Margaret, 1051-1053).

Life has been really good. I mean I've, even though I don't work. I do a lot of volunteer work. But I wasn't tired because I wasn't getting the headaches. I wasn't doing this, I wasn't, you know, I felt really good. And very, you know it was like a new lease on my life kind of thing because I'm free again. I can do, I can go out there and I can actually do something, you know (Margaret, 947-948; 1022-1027).

Adam's transition experience occurs within the context of a long history of chronic illness and past hospitalization. His perspective reflects this context:

I don't think it, for me it (being ventilated) was just another thing to get used to. For me, it was more, it was more of a downward health spiral, more of a step backwards as far as another thing going wrong or adding to, to the list of health concerns or events. As far as, you know, some people find that the ventilator has, you know, added to their life where myself if it meant being mechanically ventilated just to be kept alive, thanks but no thanks (Adam, 1026-1033)

Living with uncertainty

Uncertainty about the future is a reality for all persons; however, for ventilated individuals in this study, uncertainty was heightened because of the progressive nature of their primary disease and their dependence upon mechanical ventilation. Several individuals revealed that they had re-appraised their life. For some, this meant that life was lived, more or less, from day-to-day and endpoints for life on the ventilator had been considered.

At the time of study, three participants utilized mechanical ventilation exclusively for sleep, and those individuals recognized that their requirement for mechanical ventilation could change to 24 hours per day in the future:

And still, if it meant, you know, going on the ventilator, 24/7, it would be hard emotionally to do it. Because it's just . . . stepping back, you know, like health-wise (Adam, 1051-1054).

Now I know because I'm only on it at night, it makes a huge difference because I am free during the day to kind of carry on my life without having to contend with the ventilator. If I had to be on it during the day, yes, it would be more confining. So for some people, it probably is a much more major issue (Meg, 653-658).

Other participants had experienced respite in a LTC facility and they shared the view that they would be unhappy if they had to live there. They spoke of their fear of loneliness and dependence:

These things that I've learnt along the way, I'm kind of glad that I didn't end up there. Because you don't get with the family out there. I just didn't see them that often and you do get lonely. And I think lonely is one of the biggest things (Elise, 457-460; 464)

Institutional living you can adjust very easily to. You're, you're really cow fed. You're really given everything that they think is best for you. But I think whatever is best for the institution is not what's best for me, as I find in there. And the institution can do its best job by having the people there, you know, and looking after them. But then when they have me in it, they have an unhappy client in there (Paul, 1144-1148).

Paul hopes that he can continue to live at home, but he is uncertain about his future:

The doctor once told me not to worry about that, but I do. I said why shouldn't I? Well, he says, there's many services available 24 hours a day (Paul, 115-119).

Summary

The previous section provided the findings of the phenomenological study exploring the meaning of transition to long term mechanical ventilation for ventilated individuals living with chronic respiratory failure. Sustaining self was interpreted as

characterizing the main essence of what it meant for participants to transition to the long term utilization of mechanical ventilation. The major themes characterizing the experience of transition to LTMV include: (1) Tyranny of symptoms; (2) Self in peril; (3) Awakening to a paradox; (4) Struggling for autonomy; and (5) Life goes with a reclaimed self. The five themes, together with sub-themes, were discussed and described. The next chapter will present participant stories and thematic interpretation of family caregivers.

CHAPTER SIX: FAMILY CAREGIVER USER FINDINGS

Introduction

This chapter presents the findings of the phenomenological study exploring the lived experience of transition to long term mechanical ventilation for caregivers of individuals with chronic respiratory failure. The study question this interpretation sought to answer was: How is transition to LTMV experienced by family caregivers? In answering this question, an overview of two caregivers' stories is presented, followed by a detailed thematic analysis of the meaning of transition to long term mechanical ventilation for caregivers.

Caregivers' Stories

Leo's Story

Leo is a middle-aged man, father, grandfather and husband to Meg, who is invasively ventilated at night. He is readily able to describe the symptoms that led to Meg's respiratory crisis:

Well for three weeks, she was complaining that she was tired. And I said, OK, we'll go to the doctor. So I took her to the doctor and the doctor told her that he didn't see anything on her chest. And so I forgot how that went with the doctor. But anyway, I brought her back home. And she just kept getting worse. And when I came home . . . she was just leaning on the table. She could hardly stay awake (Leo, 45-52).

Leo knew he had to do something:

I said that's enough. Into the car, took her to the hospital. And of course that's where she was for three months. But I didn't think it was that neither but who am I to know, you know (Leo, 52-55).

In hindsight, Leo thought he should have taken Meg to the hospital sooner:

But I should actually took her sooner but she is very hard to convince to take to the hospital. And I understand because she doesn't like to be in there. But if I would have had to pick her up and take her, she was going that time because she just didn't have the energy. Good thing I did (Leo, 55-58; 64-66).

While Meg had had pneumonias and other respiratory infections in the past, Leo stated *"But it didn't seem the same"* (Leo, 85).

You know. She was just out of energy. And of course I don't know a lot about health but I sure picked it up pretty fast. But I don't know, because she, she just wouldn't go to the hospital at first. And then three weeks, she was going (Leo, 89-92).

When he saw Meg in the ICU for the first time, Leo felt despair:

Oh I thought I was losing her. Because her CO2 levels were so high. And I was very upset (Leo, 98; 106-107).

Leo spoke of the worry he felt during that time. He had difficulty articulating what it had been like for him to experience concern for his wife while also having his own feelings of sorrow. There was almost a sense of guilt for acknowledging the presence of his own feelings while his wife was close to death:

It's hard to explain because, you know, I don't sit and mope about it. It's, sometimes it does get you down but you just go on. It's very hard to explain, you know. Sometimes I guess maybe you, and it's not just being selfish, you shouldn't be feeling sorry for yourself because it's her that has the problem. But you're trying to be there for her. But it's very hard to explain (Leo, 120-126).

He felt particularly overwhelmed when the physician spoke to Meg about her condition:

He said, if you don't make up your mind what to do, what you should do, it will be made up for you (Leo, 143-145)

Leo explained that Meg was not herself; she was hallucinating. It was difficult for him to observe Meg in that state and it is only in retrospect that he recognized her paranoia had been the result of her physical state:

And well she was hallucinating. I was mad then but that's not, that's nobody's fault. I mean you have to do what you have to do. But she was the one that was, she was so anxious that she thought everybody was trying to do away with her but that was, her brain wasn't functioning properly. And I know that. Now (Leo, 147-152).

Leo identified that he was “scared”. It was troubling to observe his wife being asked to make such an important decision when she was not herself:

And I talked about it. But, you know, she was in no state to listen. It's nobody's fault there. I mean she, didn't really want to make that decision but she had to. And, but she didn't, so I can't do it for her (Leo, 186-187; 191-193).

The challenge communicating with his wife intensified Leo's sense of despair:

That was terrible. It was tough because I can't lip read. And I couldn't understand her writing because she was weak, shaky, and she couldn't write very good. And I can always read her writing but she just, Terrible - no other word (Leo, 228-232).

Leo remained present, and he stood by his wife. He was challenged by the reality that his wife was not herself. He remained steadfast, dialoguing with himself; coaching himself:

But all day I was there for the first two weeks I was there (Leo, 242-244).

And now I can see. I can see fear getting in her eyes. Straight in. Pound me. But I knew, you know what, we'll get through this (Leo, 260-262).

The hospitalization of Leo's wife affected him in many ways. According to Leo, the length of her stay in the ICU was affected by system issues and the availability of a bed in the hospital that dealt with LTMV. He continued to coach himself that there would be an end:

It was a long time. That was nobody's fault I don't think. They didn't have a room for her so they had no choice but to keep her there. That's not really what they do I don't think. But they were good (at the other hospital), I mean once she got there (Leo, 426-431).

Leo maintained hope:

I was beat, yea . . . Yea. I was beat. I was burning myself out. But I knew eventually she's going to be home and then things are going to get better (Leo, 521-523).

He described the demanding life that he lived while awaiting his wife's return home:

Oh sure it is (demanding). Anybody thinks it isn't, they'd better give their head a shake. Because it's not easy, you know, especially when you're holding a fulltime job. And you know that, I mean I had a sister-in-law that helped me a little bit. She'd come in and vacuum and dust and that was good, you know. But you still have some things to do. Outside work, you know (Leo, 529-535).

Well I think anybody in that situation should have some time off and, and visit with you and do the normal things they would do in day to day, except don't have to go to work. But, you know what, you can't live on that (Leo, 574-577).

Once his wife came home, Leo continued to work and as time passed, he began to feel more at ease. He described his growing confidence in assisting his wife with her ventilator-related needs. He spoke of changing the tracheotomy tube:

She (the nurse) showed me how to do it, and she said the next time I come, you will be doing it. OK. And I was actually; I actually wanted to do it. But I didn't know if I could. Now I haven't got a queasy stomach and I could. She showed me and the next time she came, not it's your turn to do it. And I did it. And she said, if you have a problem, here's my phone number, phone me at home, I'll walk you through it on the phone. But I didn't have a problem. I didn't even phone her so (Leo, 626-634).

I think it helped me because I was always worried about something happening at night. Do we have enough time? Especially being in the wintertime. You gotta let the car warm up and get to the hospital (Leo, 678-682).

Leo described the effect of positive reinforcement and coaching by HCP:

I think (the nurse) was a big part of that. She compliments you and she said, you can do it, don't worry about it (Leo, 912-914).

He describes the change in his sleeping pattern:

I'm a light sleeper now (Leo, 814). I used to be a pretty heavy sleeper (Leo, 818).

It's part of my life because I know it's there. And I can hear it. But I know, I guess, self consciously that alarm goes off, I wake up (Leo, 822-824).

Leo values the role of the ventilator in his life and he has developed a perspective about living life with his wife's reliance on LTMV:

It means I have my wife here so. It doesn't make a difference in our life because she's on a ventilator. Just makes a difference in our life because she's here (Leo, 1045-1051).

Bob's Story

Bob married his wife, Margaret, over 28 years ago and he describes her as being his soul mate:

We're like soul mates she's like my right arm. When she's away, I feel lost because she's not here. I probably depend on her too much for some stuff, but, uh, she really is necessary for my survival just as much as I'm responsible for my survival (Bob, 6-11).

Bob described Margaret's symptoms:

Oh, I, she pretty much just started to fade away (Bob, 53).

I noticed, uh, she would wake up tired. She would get tired very quickly. She'd wake up in the morning and say she didn't feel rested and all that sort of stuff and complained about headaches all the time: Major, major headaches. She was popping Tylenol like it was, like they were Smarties, you know, to try to get rid of the headaches (Bob, 54-59).

And one day she just didn't feel right and we didn't know what was wrong. We had no idea how severe it was. She just went with a neighbour as a matter of fact. Went to the hospital. And one thing led to the other and I got the call that they were keeping her in hospital. . . (Bob, 59-64)

I found her to be slightly incoherent, which didn't alarm me because there had been other times for other reasons where maybe Margaret was so sick that when she left the apartment she was slightly incoherent. But I guess we've gotten into this, oh it's Margaret, you know, tough, tough, tough gal, she'll always bounce back type of thing. So you're sort of maybe a little bit complacent about these annual visits to the hospital and they were annual, I can tell you (Bob, 72-80).

When Margaret was admitted into the ICU, Bob recognized that things were different than they had been in the past:

So I really had no idea how bad it was until they started talking about intubating her and moving her to ICU. Even though I watched all these medical shows on TV, I had no idea what intubation was but when they started talking about intubating her and moving her to ICU, then, then I knew that we were in trouble (Bob, 82-87).

And this, this was going to be different than some of her other visits to the hospital. So we just had to carry on from there (Bob, 87-89).

As it became clear that Margaret would not be able to survive without ventilator assistance, Bob became aware that she was expected to make a decision:

I remember that day like it was yesterday . . . when they decided that they needed to talk to Margaret about this. And they said, you guys need to decide what you want to do (Bob, 97-100).

And my immediate response was, no, I don't have any part in this decision, this is solely Margaret's decision. This is her body. She's the one that's gonna have to live with all the changes that are going to happen. So I just said to Margaret, you know, what ever you decide is fine with me (Bob, 100-106).

I just would have to be there no matter what happened (Bob, 111-112).

I don't think I was afraid of it (the tracheotomy). My attitude was more like, OK; it's got to be done (Bob, 118-119).

Bob spoke of the communication challenges that occurred as he struggled to understand Margaret:

Well my first reaction was, gee I hope this isn't permanent. You know. Because that would really, really be hard to spend the rest of your life having to write notes to everybody each time you wanted to communicate something (Bob, 226-230).

But I was concerned that she wasn't going to be able to regain the ability to speak (Bob, 234-235).

Margaret was hospitalized for several months, and so Bob found that he needed to ensure that he also cared for himself. He spoke of his experience traveling back and forth to the hospital:

I wasn't there every single day because they would have had to admit me to the hospital if I was there every day. It's just too tiring to keep up that pace all the time so I think I went every second day (Bob, 154-157).

I'm no good to her if I'm laid up myself. So if I can handle physically going there every second day, plus I was doing all my household management stuff. I was still doing my own laundry, my own cooking and all my own stuff at home. And I needed that time in between just to take care of the stuff that I needed to do (Bob, 256-262).

Bob stood by Margaret as she struggled to make a case for going home and together they learned how to manage the ventilator and prepared for Margaret's homecoming:

She was pretty determined all along that she was going to go back home. And of course I was pretty determined as well (Bob, 133-135).

Once things all settled down and I began doing the training, then I, then I felt included (Bob, 151-152).

Bob related that he was required to prove himself as an able assistant for Margaret:

Yeah I think they, I think naturally there would be skepticism. I would think they wouldn't be doing their jobs if they weren't skeptical of my ability to, to be there in a crisis. But, uh, the good folks there at respiratory that did the training, they were very receptive to everything we had to say (Bob, 170-176).

He described the feelings that arose when the time finally came for Margaret to return home:

Yeah, yeah. I was, I was a little apprehensive. But again I thought that, you know, we had covered the bases as much as we could and that it would probably work out fine. A little bit of naivety there maybe to, you know, not thinking of the big picture and thinking that we're invincible and that we can handle anything that come sup, you know (Bob, 272-277).

Bob was able to articulate what it was like to be a family caregiver preparing and waiting for your ventilated love one's return home. He spoke of the transition that he was required to make and of the scarcity of supports available to assist him through the transition:

Where is the support for me? And there was none. And I felt really, really alone and really, really angry about this. That all this attention was being given to Margaret and there was no support there for me. I was just going to have to deal with the situation as it arose and, and just hope that I was able to cope with stuff as it came up. So I was bitter. Not bitter towards Margaret. But I was bitter towards the HCP because I thought this is a major lifestyle change, there should be some support built in for the people at home that are going to be having to

deal with this situation. So, I've been real honest there that I really did feel angry about that (Bob 292-304).

Bob spoke of his adjustment to the presence and the noise of the ventilator. He also described a new proximity to his wife:

You know it sounds, it may not sound very nice but I ended up resenting Margaret because of this. I was angry and hurt. I never once spoke to her about it but every time that ventilator rang, jeez I wish that thing would stop. You know, why does that have to be doing that all the time? And I went through this whole period of every time it rang, even if she just shifted her weight around in the wheelchair, the ventilator would ring and I'd come running to see if she's OK (Bob, 319-327).

'Til finally one day she sat me down and she said, look, you don't want to be my shadow for the rest of your life. This is not a way to live. Neither one of us is going to be happy this way. So I will let you know if it's an emergency. If it's not an emergency try and relax, everything will be alright (Bob, 327-323).

He described the adjustment to the ventilator that occurred over time:

At first the ventilator was so noisy I said, neither one of us is ever going to get a good night's sleep again. You know but you become used to that. And now I think if they were to take it away, we would miss it now because it's just something that's there now. Just like a fan going or something like that, you just, you just deal with it (Bob, 390-395).

However, Bob also described a vigilance that is an ongoing presence in his life.

He describes the fear for Margaret that persists without wavering:

But, um, no she straightened me out and after that OK, I'll try it. This isn't going to be easy, but I'll try. And the feeling never goes away (Bob, 368-371).

Fear. Absolute fear that the moment I went away, that something would happen and that the staff wouldn't be there to respond if she had an emergency. And that's why I didn't make any move about employment or anything like that. I felt that my job was to be at home with Margaret (Bob, 380-384).

Bob spoke of the need to preserve himself. He indicated that one's own life could become subsumed within the work and worry associated with mechanical ventilation:

Because for the first four years that Margaret was on the ventilator, I was, I wouldn't let her out of my sight. I basically had no life. I was wherever she went, I was. Not because she asked me to go but because I insisted on going. And then

when I saw that she was doing well, and that I wasn't doing so well in a physical sense and that it was time for me to go out and do something (Bob, 470-477).

Bob provided an analogy to explain his adjustment to long term ventilation:

So it was kind of like dealing with a patient that had a heart attack, you, know, and they come home and you don't want to let them go out, you never want them out of your sights. You want to be there all the time just to make sure they're Ok. That's what I was going through and it was driving Margaret crazy and it was driving me crazy. So we really had to put a stop to that very, very early (Bob, 338-344).

After so many years caring independently for Margaret, Bob spoke about what it meant to accept formal help. He spoke of a sense of relief:

Now we've got somebody here with Margaret 24 hours a day. So now that pressure is gone. Now I feel that I can go away to work and I can be reasonably sure that she's in good hands while I'm gone and I don't have to worry about, you know, the ventilator not working (Bob, 401-405).

We should have had this kind of assistance right from day one (Bob, 525-526)

Bob shared some of his perspective on life that has evolved through living the experience of transition to LTMV:

Everyday is like you're living on borrowed time. And that's the attitude that we have. We have to be thankful for every day that she's here because without the ventilator she wouldn't be here. So we try to make the most out of every day. And if there's something that we want to do and we say, oh well, maybe we'll put it off for a while. No, don't put it off too long (Bob, 439-445).

Bob shared the following insight with me as I was leaving:

We aren't all like Christopher Reeve or Rick Hansen. We don't want people to think that we are superhuman. We just want to be ordinary and live our lives like everyone else does (Bob).

Summary-Beginning Interpretations

Being with and caring for a family member as they transition to LTMV is a physically, emotionally and cognitively demanding process. As the individual with CRF experiences symptoms that diminish their capacity to engage in life, the family caregiver is initially an observer. Over time, the symptoms become more intrusive and concerned family members become alarmed.

Crisis occurs and within the confusing world that is the ICU, family members come to know that their loved one is close to death, often observing them in an altered state of consciousness, confused or hallucinating. It is within this context that important decisions are made. Should their family member have a tracheotomy? Should they be ventilated? Both Bob and Leo distanced themselves from a decision of such gravity, believing that it was not for them to decide. They stand by and with their family member and, because speech is initially a challenge for the ventilated individual, they develop new ways of communicating together.

The family caregiver's existence bridges two worlds, each with its' own demands: the home world and the hospital world of uncertainty. They experience fatigue, frustration, and a pervasive tentativeness about life. Family caregivers pour their love, concern and energy into the work of supporting their loved one; which means that they support their struggle for independence, sometimes also being required to make a case that they can safely assist at home.

When their spouse returns home, there are many adjustments to be made. Sometimes there is frustration and resentment. A sense of vigilance, regarding their spouse's reliance upon technology, pervades their existence. This results in a new

proximity with their spouse and his/her world. Weariness and a sense of inertia sets in and caregivers initially feel that life is somehow “on hold”.

Over time, there is adjustment that results in a sense that life can and does go on; however, for the family caregiver of a ventilated individual, there is always a sense of fear that something might go wrong.

Thematic Analysis

Transition to long term mechanical ventilation: The lived experience of family Caregivers

The previous section presented two of the participants' stories, and provided a beginning interpretation of them. This section builds upon those beginnings and presents a thematic analysis of the experiences of the participants being with and caring for their family member as they transitioned to long-term mechanical ventilation (LTMV).

The interpretation included: the experience of being with the family member as they manifest and live with the symptoms of chronic respiratory failure and, the event or events that precipitated their admission into hospital, the period while ventilator users were in the ICU and other hospital units, the experience of being with the ventilator user as they return to their home in the community or relocate to a long term care facility, and the experience of life at home with their family member on LTMV. As with ventilator users, presenting the findings in this way is intended to facilitate the inclusion of important contextual background from which to reveal the meanings that the participants attribute to their experience of transition.

The Essence: Sustaining the Family

For the participants in this study, the overall theme or essence of the meaning of the experience of transition to long term mechanical ventilation is *sustaining family*. For family caregivers, the meaning of the transition process was entrenched within the meaning of being a family: being a spouse, a daughter, a sibling. Love, commitment, and partnership were in evidence within the words and stories of caregivers.

Helen described the role of the main family caregiver:

I think you would find that in most cases. There's one person that is central. The one that everybody goes to find out . . . well who do I call for this or who do I call for that? Or when this happens, you know, what is the protocol for doing something (Helen, 563-567)?

Alex bristled at the idea that he was anything more or different than a husband:

I don't consider myself a caregiver, I consider myself a husband. So regardless if Elizabeth has MS or a broken ankle, I mean it's just part of a partnership (Alex, 405-408).

He explained that the main reward of being a family caregiver was being together with his wife:

Well reward is seeing her sitting beside me (Alex, 405-409).

Leo also described what it meant to have experienced transition to LTMV. He was grateful that the family was together and that his wife continued to be in his life:

It doesn't make a difference in our life because she's on a ventilator. Just makes a difference in our life because she's here (Leo, 149-1051).

Krista shared her perspective that transition to long term mechanical ventilation was not only experienced by the individual with chronic respiratory failure, but by the entire family:

You recognize that you're all in this together and for nobody to, you know, nobody to think that it's just the person that has it (Krista, 1217-1218).

Helen revealed a conviction that the preservation of family was what had sustained her sister's will to live:

And because we were a close family before, then she, she wouldn't have been, she would not be alive today if she were in (a long term care facility). Like, like where she just, she would have shrivelled away to nothing. Her will to live would not be there anymore. Because she was always such an outgoing person and thrives on people being around her and talking to people and family being there and all that kind of stuff (Helen, 276-283).

Participants in this study reveal that they had been central to a struggle to sustain their family through an exceedingly challenging process of transition. Ultimately family

caregivers came to understand that in order to sustain their family; they also needed to work to preserve themselves. The awareness developed through the passage of time. Participants, who had been with ventilated family members for many years, articulated the notion that “*you don’t go into this for the short term. You’re going into this for a long time*” (Helen, 467-468).

For most participants the period of transition began with a crisis event, but for others the period of time predating the crisis was also steeped with the living of transition. Leslie exemplified the drive to preserve family. She revealed that she was a “worrier” and that among all of her worries, her husband’s breathing was “*probably the biggest one*”. Over the course of her married life, a variety of ventilator technologies had been integrated into her experience of being a family. She described the rocking bed.

It was a rhythmic sound and when we were on holidays, he had that homemade rocking bed in the trailer that we had. Travel trailer. And they’d turn around and say, dad, come on, get into that rocking bed. We can’t go to sleep until you start the rocking bed. So that was very positive too (Les, 61-66).

As with ventilator users, family caregivers also revealed transition to be a process that encompassed several events, all of which were significant in the overall meaning of their experience. Five main themes, concerning the participants shared experience of transition to LTMV emerged. Each theme characterized how participants made meaning of their experience. These themes are: (1) *Intrusion of symptoms*, (2) *Being there*, (3) *Bridging two worlds*, (4) *Making peace with the ventilator* and (5) *Life goes on with a new vigilance*. Each of these themes has several sub-themes that together comprise the main theme (See Table 6.1).

Table 6.1
Family caregiver themes and sub-themes of sustaining family: The lived experience of
transition to long-term mechanical ventilation

THEME	SUB-THEMES
Intrusion of symptoms	<ul style="list-style-type: none"> • Witness • Alarm
Being there	<ul style="list-style-type: none"> • The confusing world of ICU • Communication challenges • The decision: It's not mine to make
Bridging two worlds	<ul style="list-style-type: none"> • Life is on hold • Bureaucracy
Making peace with the ventilator	<ul style="list-style-type: none"> • So much to learn • The machine: friend or foe? • New proximity
Life goes on with a new vigilance	<ul style="list-style-type: none"> • Planning • Attitude/Gaining perspective

The Intrusion of Symptoms

In this study, caregivers revealed that they were initially onlookers, or witnesses, to the manifestation of symptoms of chronic respiratory failure. As the individual with CRF became more adversely affected by symptoms, family caregivers recognized that symptoms were intruding upon the family's way of being. They became increasingly alarmed and were often the force responsible for seeking medical assistance. Many participants described what it was like to observe their family member "*fade away*".

Leslie recalled being newly married to a man who was struggling for breath:

Well that was early in our marriage when he would sit up at night in order to get enough air again. I had no training on that so I had no idea what to do (Les, 15-17).

She also recalled her spouse's difficulty breathing following meals and his acknowledgment that painful headaches affected every morning:

Oh yes, he told me his headaches were lasting until noon (Les, 72-73).

After meals was the most difficult time. He eats anything. And he loves to eat. And he just couldn't eat as much as he wanted to because then he couldn't breathe (Les, 101-103).

Being there

When the individual with CRF experienced a physiological crisis, family caregivers were thrown into the confusing world of the ICU, where communication with their family member was often impaired by a mask, endotracheal tube, and/or an altered level of consciousness. In the midst of crisis, confusion and their own despair, family members reveal being drawn into a life or death decision making process. Being there characterized what it meant for family caregivers to be present at their loved one's bedside, like steadfast sentinels within an unfamiliar world:

But all day I was there for the first two weeks I was there (Leo, 242-244).

It's so overwhelming going into the city of course, into, thrown into the medical system right away when you don't really know what all's going on. Where you're supposed to be going. And all these pieces of equipment. And so it is a, quite a shock to you to see all this stuff. . . they don't totally explain everything to you. You just kind of go in and see the person. Then you're thinking, OK, well why do we have this and why do we have that. And there's nobody really there to say, well we have her on this because of this and because of that (Helen, 60-70).

Being there also characterized the meaning of being present and providing support in the face of a life or death decision. Family caregivers believed that such a decision was not theirs to make:

And my immediate response was, no, I don't have any part in this decision; this is solely Margaret's decision. This is her body. She's the one that's gonna have to live with all the changes that are going to happen. So I just said to Margaret, you know, whatever you decide is fine with me (Bob, 100-106).

I feel I somewhat put myself in the background because I don't want my decisions or my thought process to affect Elizabeth's process. I mean ultimately it's her decision whether to be vented or non-vented or what process she wants to follow through. And I've just always said, whatever she decides I'm just there to support her. So, again I, I don't feel I've been in the background although in a sense I put myself in that position sometimes (Alex, 82-91).

Communication challenges were very distressing for family caregivers. Often caregivers felt the need to represent their family member to health care professionals who did not know the ventilated patient as a person. This was another reason why caregivers maintained their presence at the bedside:

It really seemed like they kind of forgot about her as a person for a while. That, yes, she can still hear. And she does need eye contact and she does need reassurance and that type of thing. And everybody kind of seemed to talk over her for a while. You know like them forgetting that, you know, there is still a person here very aware of what's going on around them but she just can't speak to us right now (Helen, 72-77; 89-91).

It was not only the endotracheal tube or mask that affected communication. Being with the ventilator user while they experienced an altered mental state was very disconcerting:

And well she was hallucinating. I was mad then but that's not, that's nobody's fault. I mean you have to do what you have to do. But she was the one that was, she was so anxious that she thought everybody was trying to do away with her but that was, her brain wasn't functioning properly. And I know that. Now (Leo, 147-152).

Bridging two worlds

While the individual with CRF spends months to years in the hospital, the family caregiver is caught between two worlds. They spend a good deal of time at the hospital, being with their ventilated family member, and they often continue to work and keep up the maintenance of their home and family. Fatigue, and a pervasive sense that life is somehow on hold, dominates their existence:

It was hard because you're putting in a long day working. And at that time, I still worked overtime too. And, I knew that when I finished work, I went straight to the hospital. And then I stayed there until about 830 and then I'd come home, had supper and watched a little TV maybe and went to bed. But I mean it is tough. But it didn't really bother me. I knew that eventually she's coming home so . . . (Leo, 470-475).

Difficult days were spent at the hospital by the caregiver:

You want her to get better faster. . . Like she was very pessimistic that nothing was going to change. And this is wrong and that's wrong. And, yes, she has every right to be grumpy and angry. And it's hard to remember that, you know when she does have a bad day (Helen, 186; 212-215).

The fact was that my mother was really, really angry and frustrated that she wasn't at home. So it was getting really difficult to deal with her because every time we went in, she's going, are you taking me home? (Krista, 915-919)

As their loved one's symptoms subsided and renewed energy was exhibited, caregivers were delighted:

And I went holy, you know, I didn't realize how bad she was looking before that, you know. Like suddenly she had colour in her face (Krista, 413-415).

So more than anything else I was really excited and I was really glad that she decided to do that (ventilate), you know and that was really good (Krista, 424-427).

However, participants also revealed that there were new challenges to contend with and there was heightened anxiety and uncertainty about the future as they waited:

Well kind of an emotional strain. You didn't know where you were going. Although I wanted her to be home. I didn't like the aspect of maybe LTC. That wasn't my option but, so I think it was just the unknowing, waiting it out to see where you were going to, and what door was going to close on you next or which one was going to open (Alex, 206-207; 211-215).

Participants found it difficult to stand by as the ventilator user made a case for self-determination and the opportunity to choose how, and where, they would like to live.

They recognized that there were a number of barriers to independent living:

Some of the social workers just wouldn't believe Elise. Like she kept saying, I want to come home. And they'd say, well no, that really can't be done, you know,

we're not set up for that. People like you don't live out in the country. We've got this good facility here. And they just wouldn't listen to her that, hey, I want to go home. And I said, Elise you just keep telling them that because some day you will get home (Helen, 250-257).

They shouldn't be told where they have to live (Helen, 319-320).

Like my mom knew what she wanted to do and we were pretty sure she could handle it and there was some staff available and so what's the problem. But it seemed to be such a rigmarole, you know, to have to go through everything. So that was the hard part of it (Krista, 932-936).

She was pretty determined all along that she was going to go back home. And of course I was pretty determined as well (Bob, 133-135).

Krista revealed that the attitudes of health care professionals were difficult for her to experience. She felt that she needed to defend her mother's choice to live:

So I found that really difficult; just attitudes and, the sheer surprise of people. And having to defend my mother's life . . . (Krista, 621-622).

Making peace with the ventilator

As ventilator users returned home, caregivers experienced a very significant change in their experience of proximity with their family member. As a result, they were also confronted with the reality of the ventilator, which they often referred to as "the machine":

Again, I think it's been the hardest transition, again, because it's a machine. The other, the diagnosis or knowing that you're not attached to a machine, I always felt you could overcome it. But now, you're not in control. The ventilator is in control ultimately. So, yeah, it's been the toughest transition for me, just being strapped to a machine (Alex, 318-324).

A conflicted relationship between the family caregiver and the machine was illuminated through descriptions of fear and frustration, as well as gratitude. Participants explained how their acceptance of the ventilator had been a process that included: learning about the machine; fearing the machine; being frustrated and angry with alarms,

sounds and the presence of the machine; troubleshooting problems with the machine; and ultimately, recognizing that one had some control over the machine.

There is so much to learn

Family members described the formal process of education that they had undergone in order to learn about the tracheotomy and the ventilator. They revealed that there was a lot to learn and they valued what they had learned:

Once things all settled down and I began doing the training, then I, then I felt included (Bob, 151-152).

I did appreciate learning about (the ventilator) at the hospital, you know . . . so I would definitely recommend just to, just to alleviate the stress that's going to be there no matter what a little bit, that some sort of training would be good if you're going to be a caregiver (Krista, 1260-1261;1266-1269).

For me that was comforting, just getting an idea of how it worked, you know, and learning about the, well the humidifier and how it heated things and why. And, you know, just all the connections and just seeing it all done (Krista, 1287-1291).

As they continued to learn about the ventilator and HCP discussed how to troubleshoot problems that might occur, a seed of fear began to grow:

Well there, it was mostly that I had so much training in such a short time, would I remember everything? (Les, 390-393).

And then they had a family conference and that sounded like we would be having for more problems than we ever did. You know they made it sound far worse than it was. And when we got through, I said to my children, I only think the two were there. The other two were away. I say, what's your impression of the meeting we had? And my younger daughter, she's real down to earth; she says, well let's just wait a while. Alright, and those many things that they thought might happen never did (Les, 391-400).

I think they could prepare better with a more positive outlook and attitude on their behalf. It would seem to me, for the most part, their attitudes were more of the doom and gloom and the, and all the down sides. And, which kind of scares the hell out of you. With that being said, maybethey do that to try and prepare you for the worst and hope for the best, I don't know. But they could temper it with a little, throw in a couple of positives once in a while. So I think mentally prepares you. That's how the medical profession can help in this case (Alex, 365-375).

The machine: friend or foe

Participants revealed that the ventilator initially commanded much of their concern and they experienced mixed feelings about the machine:

Yea, because I didn't like the machine but at the same time I was really glad of what it was doing for her, you know, I wished there had been another way but, you know, but there's not (Krista, 483-486).

Yea, oh yea. I was afraid of it. I was definitely afraid that it was going to break down. And I mean if it was all working as it should have been, that didn't scare me at all. But, more than that, the biggest thing, my biggest feeling when she first got ventilated was, I was relieved and excited because she looked 100% better the first day (Krista, 396-398; 404-407).

Alex described the ventilator as a double-edged sword: its omnipresence making manifest the reality that his wife could no longer breathe:

I mean now you're attached to a hose, which, prior to being vented on the Bipap, you knew her breathing was going downhill but she still had the ability to breathe on her own. So it gave you that little bit of breathing room. You know if something went south. I don't know, a problem, at least, at least you weren't dealing with the inability to breathe. So, yea, now you, it's a, it's a double edged sword. So I mean it's her lifeline obviously, not to sound wonky, but it's exactly that: A life line. You know you're on a 4 foot cord (Alex, 234-243).

Family caregiver's were affected by both the size and sound of the ventilator:

And well, you know, the only part of the vent I find annoying or frustrating is the size of the damn thing because I know that there's smaller one's out there. And it would be nice if it didn't weigh 600 pounds and take up a half of a room, you know, because that's very frustrating (Krista, 696-701).

Participants described a kind of inner dialogue that transpired between themselves and "the machine":

I'm going, oh my God, like what if it breaks. Cuz fine, you've got your resusc bag and everything else, sure, you know. But I mean that was, just the whole issue of it being around, you know. But I found that was more of just getting used to the thing. Just getting used to it and realizing that, yes, it is a machine but plenty of other people use these machines. And chances are it's going to be fine and what not (Krista, 385-392).

As participants spent more time with their family member and the ventilator, they began to be less fearful of the machine. A variety of experiences contributed to the adjustment.

Leo revealed that his level of stress had diminished somewhat after he was reassured that paramedics would respond quickly. He had called them one night when Meg experienced difficulty breathing. The incident helped to assure him that he and Meg were not completely alone.

They were here in no time. And even the paramedics were actually laughing because that was the first time they had ever took anybody to the hospital that bagged themselves. I think it helped me because I was always worried about something happening at night. Do we have enough time? Especially being in the wintertime. You gotta let the car warm up and get to the hospital (Leo, 678-682; 689-691).

Knowing that others had successfully managed long term mechanical ventilation at home helped Bob to cope:

I think the big thing for me was the knowledge that other people had done it already. And if they can do it, we certainly can do it (Bob, 634-635; 639).

Confidence grew when the nurse visited Leo's home and provided him with encouragement and coaching regarding tracheotomy tube changes:

She (the nurse) showed me how to do it. And she said the next time I come, you will be doing it. OK. And I was actually, I actually wanted to do it. But I didn't know if I could. I haven't got a queasy stomach and I could. She showed me and the next time she came, now it's your turn to do it. And I did it. And she said, if you have a problem, here's my phone number, phone me at home, I'll walk you through it on the phone. But I didn't have a problem. I didn't even phone her (Leo, 626-634).

The ventilator affected the caregiver's sleep quality:

I'm a light sleeper now. I used to be a pretty heavy sleeper (Leo, 814; 818).

I'd say it's (sleep pattern) changed I think in a way. I go in cycles sometimes where I don't sleep all that well and other times not too bad. I mean you don't know if you are hearing a weird sound in the thing or what you're doing or. And

you don't know if the alarm's going to work which we've had a couple of incidences of that which. So, yes, my sleep has been affected I think for the worse (Alex, 296-301; 291-293).

Bob spoke of his adjustment to the noise of the ventilator:

At first the ventilator was so noisy I said, neither one of us is ever going to get a good night's sleep again. You know but you become used to that. And now I think if they were to take it away, we would miss it now because it's just something that's there now. Just like a fan going or something like that, you just, you just deal with it (Bob, 390-395).

New proximity

For caregivers, the homecoming of their family member was eagerly anticipated. However, it also heralded a significant change in the way that life was lived, as participants experienced a new proximity with their spouse, sibling or parent. Family caregivers sometimes felt that “*there was no space*”.

The caregiver role exposed Krista to a new and, sometimes uncomfortable, intimacy with her parents and their world:

I've been involved in their relationship of course to some extent. But it was kinda different being there 24/7 and, you know, not like I couldn't walk away if they were arguing because I was supposed to be there caring for my mother (Krista, 190-193).

And I just felt I was too involved and not to mention the fact that then, because I was there right after any sort of conflict may have happened, my mother felt the need to talk to me about it (Krista, 200-204).

The perceived need for close proximity was exacerbated by a lack of trust in the reliability of the ventilator. Krista felt that she must stay close as she had experienced an alarm malfunction early in her care giving experience:

So I think from that point on I probably held on to the ventilator and stuck by her side for every second because I was scared to death. But, you know, that just came with time I think, more just getting used to the idea that it kind of works most of the time. Just be more careful (Krista, 430-431; 445-453).

Life goes on with a new vigilance

We are both of the attitude where this is the hand you're dealt so make the best of it. That's what we're doing. It's sure not what both of us had envisioned. But, uh, life does go on (Alex, 65-68; 72).

Family caregivers needed time to adjust to living with a kind of basal fear, or a fear that never completely subsided. While confidence in their ability to manage the ventilator developed, caregivers resolved that the machine could not be permitted to take over their life. Planning became a vital component of everyday. Eventually, each participant developed their own perspective regarding living life with a loved one reliant on LTMV. *"Life goes on with a new vigilance"* characterized what it meant for family caregivers to develop a routine and begin to enjoy "normal things" with their ventilated family member. While the tangible difference in their life was "the machine" the intangible difference, shared by all caregivers, was a new and ongoing vigilance.

Vigilance also remained an enduring concern for the caregiver with a family member in a long term care facility. There was an ongoing preoccupation with the safe functioning of equipment, as well as a concern as to whether or not health care professionals were effectively meeting the needs of their ventilated family member.

Alex revealed that even when home assistance was increased to 24 hours per day, his sense of vigilance remained unchanged.

Prior to 24 hour assistance:

Different only in that it's a little more taxing. I mean you know. I mean your sleep and everything else, it's just sometimes maybe, you think, it would be nice to share the workloads with somebody else (Alex, 419-422).

Following 24 hour assistance:

You're never removed. Just because you're not physically, uh, helping. I mean you still have the, again as I said earlier, you're always cognizant of what's around (Alex, 432-435).

Krista and Leslie spoke of strategies that they employed in order to minimize the fear that had developed over time:

Well just one day at a time and it worked fine for me (Les, 426).

And just getting used to the whole, what you have to do and pay attention to and getting the monitors in place so that if I did leave the room for a minute and the vent didn't go, she, well, she clicks with her tongue (Krista, 456-461).

Planning

Participants experienced a very real change in their sense of personal and family freedom. Preparation and planning became integral to family life. Spontaneity was not possible; however, with forward planning, participants discovered that they were able to participate in selected family and social activities:

That, you know, you're limited to places you can go. The time it takes to get places, do things. And it's just all a part of life now. And you learn to work your schedule around it (Helen, 433-435).

I mean it's not that we can't do things now, you know, it just makes it a bigger issue in terms of planning and everything else. Well it's changed in terms of, well being able to do things is a much bigger issue now, you know, just because she has to have, um, well she has to have a care provider there, you know (Krista, 694-696; 689-691).

Wheelchair accessibility was identified as another concern necessitating forward planning. One participant revealed that the Christmas celebration could only be held at one family's home, as it was the only one with wheelchair accessibility. Sometimes individuals within the family expressed frustration and/or resentment that family life was altered by mechanical ventilation. Caregivers became advocates and teachers within their own family:

It's been an eye opener. Like you really become more aware of the handicap situation in the world. What's accessible? Uh, probably my kids become somewhat resentful that we have to check on different venues first before, to see if Elise can go there before we go as a family. Like the whole group of us that is. . .

... this kind of steps a little more into their lives than they want it to (Helen, 355-366).

Planning was also the strategy employed to minimize role strain. Helen described her need to balance her caregiver role with her other responsibilities as wife and mother. She recognized that she needed to be the one to ensure that the ventilator did not take over her life, and this meant talking to the VAI about her situation:

And like I've told her [VAI] like they're, they come before you [her children]. And even though you might not like to hear that, but I have to look after them, make sure their healthy and well and then I can look after you (Helen, 503-507.)

Family caregivers were occasionally uncomfortable with what they perceived to be complacency on the part of the ventilator user. Family caregivers felt exceedingly responsible for the safety of their ventilated family member, and they could not suppress their sense of vigilance. Sometimes it became evident that there was a tension between the ventilator user and the family caregiver:

I thought she drove her chair too fast. She was too reckless. She was going to tip that thing over because she didn't slow down when she was going up and down curbs. And I was constantly nattering at her and she'd keep telling me to shut up. She knew what she was doing and stuff like that. But I was not as fearless as she was (Bob, 418-423).

The following excerpt is an exchange between the Meg (ventilator user) and Leo:

I know even for myself when I first came home, don't go anywhere without your suction machine, don't go anywhere without your bag and your trach. Make sure you take your this and that. Syringe. yeah. I just felt like I couldn't go anywhere without a whole paraphernalia thing. Now I might keep my suction machine if I'm having a day where I'm feeling like a little more suction, but basically I pick my purse up and go (Meg/Leo 736-743).

We usually take it with us. But you're not supposed to go without that suction machine (Leo, 745; 776-777).

Attitude/Gaining perspective

Within an existential phenomenological perspective, the ability to see and focus on the positive aspects of stressful or distressing experiences is a way of creating meaning (Farran, 1997). Helen does this when she speaks of the experience of transition to LTMV as being one of learning, which has broadened both her children's and her own understanding of life:

But I think they've become better kids because of this. And I think we all have. You know, with, um, patience, understanding that life can change very fast. It's not as we planned. And we make adjustments to what we have. Like with Elise, it hasn't been all bad. And so they're learning and we're all teaching (Helen, 392-399).

For participants in this study, the meaning of the experience of being with a family member, as they transitioned to the utilization of long term mechanical ventilation, was derived from suffering and despair; frustration and loss; as well as gratitude and fulfillment. Participant's stories provided narrative accounts of their perspectives, which were illuminations of meaning.

Krista talked about the ultimate significance of LTMV in her life, and how the meaning of mechanical ventilation was intertwined with her mother's quality of life:

Well it's, well for me it's meant that my mother's not dead. Because I know she would be dead if she wasn't on a vent. I mean that's pretty obvious, you know, so far, for me, that's, I mean that's the biggest thing you know. I mean of course, the majority of daughters don't want their mother's to die, you know. Well I mean I know she's going to of course. But I'd rather it be later than sooner if at all possible. And, but also, I don't think I'd be saying that if I didn't think that she had a quality of life, you know (Krista, 636-639).

Krista's perspective is embedded within her love for her mother and her desire for her mother to experience autonomy and choice. Her perspective enmeshes her past knowledge of her mother as a person, her present understanding of her mother's circumstances, and the uncertainty of the future:

You know right now she's feeling pretty good but she doesn't know what it's going to be like once it gets to the point when she can't speak any more. And she has said that, well she said that she, she wants to continue on with as long as she can communicate somehow, you know, and get her needs across . . . I mean it's all her decision in that way, you know. I mean not that I won't talk to her about it. But you know, I definitely believe that that's her choice (Krista, 1166-1169).

Bob's perspective was also entrenched with the notion of time:

Everyday is like you're living on borrowed time. And that's the attitude that we have. We have to be thankful for every day that she's here because without the ventilator she wouldn't be here. So we try to make the most out of every day. And if there's something that we want to do and we say, oh well, maybe we'll put it off for a while. No, don't put it off too long (Bob, 439-445).

Leslie described her perspective of what it had been like to live with a man who had undergone many ventilator transitions over the years:

In one word . . . Different. Not impossible. A challenge. Rewarding . . . Rewarding in the fact that his health is not deteriorating. I don't think my health is deteriorating. We both have good appetites. We help each other. And, uh, we do fun things together. Like we have beautiful parks. . . (Les, 643-658)

She continued to illustrate what it meant to have experienced transition to LTMV by painting a tranquil and evocative picture with her words:

And, and I like it when, in the evening if it's nice out, a wonderful day, the blue sky and it's warm, not too hot. And then he goes around town and just looks at things and sees. Reports back what's happening here, there and everywhere. Sometimes I sit outside in the sunshine too (Les, 663-670)

Alex expressed the meaning that he ascribed to his spouse's ventilation:

Well it means I, uh, it means I have my world back. It means everything to me. Just to. Her physical capabilities are limited now but knowing that she feels better physically and mentally because she can breathe and being vented, the spill over is it makes me feel better (Alex, 220-224).

Helen and Leslie spoke of the fulfillment in the caregiver role:

I feel good about it. Like a fulfillment that I'm making sure she's getting the best possible care. That I'm seeing improvements in her. That I'm trying to make her life better for her. That she is getting some enjoyment out of life and making her realize that there are things that I can still do and that I'm going to push myself towards. Uh, getting her out and about. Not rushing things for her because, I

time to speak or trying not to interrupt her or giving her the time to vent herself, like when she's angry, that she has a right to try to yell or raise her voice if she can do that (Helen, 641-655).

Summary

The previous section provided the findings of the phenomenological study exploring the meaning of transition to long term mechanical ventilation for family caregivers of individuals with chronic respiratory failure. Sustaining family was interpreted as characterizing the main essence of the meaning of transition to the LTMV as a family caregiver. The major themes characterizing the experience of transition to LTMV include: (1) Intrusion of symptoms; (2) Being there; (3) Bridging two worlds; (4) Making peace with the ventilator; and (5) Life goes on with a new vigilance. The five themes, together with sub-themes, were discussed and described.

Comparison between ventilator user and family caregiver lived experience

The third question that this study sought to answer was: What are the similarities and differences in the meaning of the transition experience for individuals with CRF and their family caregivers?

During transition to LTMV, family caregivers and ventilator users are both confronted by significant psychological, physical and spiritual challenge. Their endurance and commitment to sustaining self and sustaining family is tested many, many times. While the ventilator user is hospitalized and the caregiver lives at home; their lives are lived on dual tracks, and proximity with one another is an issue. As VAI carry out the psychological and physical work of adjusting to ventilation, caregivers experience physical and psychological work as they try to maintain two worlds. Both the VAI and the family caregiver dedicate time and energy to learning about the ventilator, and when the VAI finally returns home, there are significant adjustments to be made.

Once again, proximity is an issue as ventilated individuals and caregivers adapt to a new closeness with one another. The VAI has had time to adjust to the physical presence of the ventilator, internalizing what it means to be reliant on technology; however, caregivers have not lived the same experience. Here is where the living of the experience of transition to LTMV particularly diverges for caregivers and VAI.

Family caregivers experience an ongoing sense of fear regarding their loved one's reliance upon technology. While they eventually understand much about the workings of the ventilator, and they are grateful for the presence of the ventilator in their life, they cannot dismiss their fear. So caregivers maintain an ongoing vigilance regarding the ventilator, even as life goes on. VAI experience uncertainty about their future; however, their past experiences of symptom distress, and being close to death, provide meaningful context for their perspective of life going on.

CHAPTER SEVEN

Ventilator User and Family Caregiver Recommendations

Harvey (2000) explains that “loss becomes gain as we heal and particularly as we use our losses and what we learn from them to contribute to others who also suffer” (Butcher & Coen Buckwalter, 2002, p.114). As ventilator users and family caregivers shared their stories, it became evident that they had gained valuable wisdom through their unique and shared experience of transition to LTMV. Their narrative provided both direct and implied advice and recommendations for health care professionals, ventilator users and family caregivers. It was evident that the participants in this study wished to contribute to the lives of others. The following section will provide an overview of the advice participants offered.

Participant recommendations and advice will be presented under the following categories: (1) Equipment related issues; (2) Health system and health care professional issues; and (3) Recommendations for potential ventilator users and family caregivers.

Equipment related issues

All equipment, whether it is a ventilator, suction apparatus, wheelchair or mechanical lift, represents a means of facilitating independence; thus equipment was highly valued by all participants. When equipment was working effectively, the lives of participants proceeded as expected, for the most part. Issues concerning the effective functioning of equipment were central to the lives of participants.

Participants recommended improved timeliness of access to modified wheelchairs. The utilization of mobility aids had predated many participants' experience of transition to LTMV; however, several participants indicated that one of the reasons

they were hospitalized for such a long time was because their wheelchair needed to be modified for ventilator use. This issue affected length of stay and also resulted in ventilator users being confined to their bed or their hospital room. In addition, once participants left the hospital, wheelchair issues continued.

One caregiver participant related that he'd had significant difficulty accessing a wheelchair for his wife. It was his initiative in looking for parts that facilitated his wife's access to a chair.

Other participant's used their ingenuity and financial resources to ensure mobility:

I have back-up (wheelchairs). I'm not stuck if this SMD wheelchair that I'm using fails. Get me to my own that I have built, basically prepared and built on my own, out of my pocket expense too so that it'll accommodate me in the house, or out of doors. But also it'll take me into my van which is a motor vehicle transportation I need from time to time. The government chairs won't. They're too big for my van (Paul, 1245-1253).

Leslie indicated that Paul's chair was essential to their ability to live their life together. She prioritized her efforts to ensure that they were working efficiently:

I try very hard to check all the cords; whether they've all been plugged in so that the chair will . . . , every part of the chair will work. Like some chairs have more plug-ins than others. And because we have three different chairs, you have to know where to plug in, where on each chair (Les, 583-588).

Leslie noted that without Paul's ingenuity and mechanical skill; they would have had to rely upon a system that they perceived to be less than reliable:

Like we were expecting new belts for this chair today. They were promised to us to be in the mail today and they weren't. So we hope and pray that these belts will hold for another night (Les, 969-972).

Access to wheelchair maintenance and parts was also of concern:

Like there's been times . . . my mother's been in her bed for a week at one point, well six days, because her chair had to be fixed and she had no other option, you know (Krista, 1346-1349).

Access to equipment was of particular concern to individuals living outside of the city:

There's been twice where she's been given a bag that had the wrong end on it. So it didn't attach to her thing. And that wasn't realized until the bag was needed. So, I mean, it all ended up all working out fine in the end. But had she been in the city, we would have been able to probably sort that out that day instead of having to call then man to get another one sent out . . . (Krista, 1374-1381)

Tell them don't ignore services when those are needed for my ventilator and both you and I are incapable of solving that problem and we need replacement of ventilator or parts thereof (Paul/Les 960-963).

Several participants disclosed how important it was to find the right tracheotomy tube. Meg was able to garner information about tracheotomies over time, and she eventually came to wonder why she was constantly inflating and deflating her cuffed tracheotomy tube. She took the initiative to discuss this with her health care provider:

I just knew that, like they had said we have uncuffed trachs and cuffed trachs. So then I got to thinking, . . . well, OK, uncuffed. Because when I'd go on the ventilator at night, I would always start uncuffed, just sort of to get in synch with the machine. And I'm thinking, well if I can do it now, why can't I do it all night. And so that was when I broached the subject with the doctor. And everything worked out well. And I'm really pleased (Meg, 551-558).

Participants questioned why the ventilator needed to be so large and so noisy. Many individuals had become aware that there were smaller models available on the market:

The older style ventilators are very, very intimidating. You really do feel like you need a medical degree in order to operate one of those things. The newer ones are very user friendly, um, as long as you know what all the alarms mean and stuff (Bob, 671-675).

For the most part however, the ventilator had been reported to be fairly easy to use and the delivery of supplies had been quite reliable:

The ventilator itself is not a lot of troubles. It really isn't. I have a bedside one and a chair one so you know; we just transfer back and forth. And it's easy to

keep clean. I haven't had any problems. I, uh, I'm fortunate, I haven't been suctioned for a long time (Elizabeth, 796-800)

Ventilator users and family caregivers continued to require advocacy skills long after their initial adjustment to LTMV. Equipment availability and efficiency was integral to their ongoing ability to live their life.

Health system related issues

Health system issues were described throughout both VAI and family caregiver narratives. Participants made recommendations in the following areas: peer support initiatives, family involvement and caregiver support, length of hospital stay, support for home ventilation, support for rural communities and issues related to re-hospitalization.

Peer support initiatives

In the initial process of transition to LTMV, health care professionals had arranged for Elizabeth to meet a ventilated individual who resided in a LTC facility. Elizabeth believes that it would also be very helpful for prospective ventilator users to visit someone living at home on a ventilator. In the early stages of her illness, Elizabeth found it difficult to imagine what it might be like to live at home on a ventilator. She also thought it would be helpful for physicians to see what it was like for a person to live at home on a ventilator:

It is hard to imagine. You see the ventilator in the doctor's clinic or whatever, you know, and just so they (prospective ventilator users) can see and understand that.

In fact . . . I think it would be good for doctors to understand that (Elizabeth, 853-856).

Elise also believed that it would be helpful to be connected with other ventilator users in order to share her experiences and learn from others:

I don't think I'm the expert, but I do think that at one time or another people need to talk to other people in the same situation (Elise, 1065-1067).

Family involvement and caregiver supports

Both ventilator users and family caregivers were concerned about the stress that was experienced by family members during the transition process. The primary relationship of three ventilated participants had unravelled during the transition process; as a result, there was particular concern that family be adequately supported. Bob shared his experience of frustration, and anger. He related that the family caregiver was expected to support the VAI, yet there seemed to be little support for the struggles of the caregiver:

Just to have someone that you can talk to when you start to get these feelings of hopelessness or anger and resentment. And a place where you can go to talk that through so that you don't end up blowing up at the person that's using the ventilator when we just can't take it anymore. Because that doesn't do either one of you any good (Bob, 648-653.)

The people, the family have to be involved. Be involved every single minute of every single day. Because knowledge gives you experience and the experience helps you cope with the unforeseen things that are going to come up. So you have to be involved every, a bit of every day. Not so much the medical stuff. Like I still don't understand all the physiological reasons why Margaret is on a ventilator and how the whole upper respiratory system works or all that stuff. You don't need to know that stuff. You just need to know what to do in case of an emergency. That is the most important thing that you have to learn (Bob, 547-557).

In order to minimize caregiver fatigue, Adam recommended including as many family members as possible in the education process:

Sit down and almost have a family conference type thing so that either a caregiver or family member can get the information without it having to go second or third hand. Even though they're only worried about the initial caregiver . . . so if the caregiver needs, you know, to take a break sometime, if that means, you know, taking a break. There's more than one person that knows what to ask (Adam, 1114-1117; 1126-1133).

While some caregivers found support groups helpful, others preferred individualized support:

I do find it's helpful to talk to other people who have been caregivers, or who are caregivers or whatever the case may be. Like I've gone, you know, I go to the

odd support group meeting and that has been helpful, depending on the topic (Krista, 1229-1223).

I mean there is a support group but both of us have been there before. And when I say there isn't support, they try to have support but I think it's so relative, uh. I didn't find support there although maybe somebody else might. So, uh, I'd answer no there isn't support (Alex, 106-111).

I felt that Mom really needed counselling at the time. And that was never offered to her (Helen, 233-234)

Length of hospital stay

Participants recommended decreasing the length of hospital stay for ventilator users. They indicated that protracted hospital stay was often the consequence of operational, health and social issues, and unrelated to physiological need. Elizabeth remembers being very frustrated and thinking, "OK, let's go now". Meg expressed satisfaction with most aspects of the transition process, except her length of hospital stay. "If they could make some improvements there, I think that could help some people too" (419-420).

Support for home ventilation

Several participants perceived HCP as being bias toward sending ventilator users to a long term care facility. They recommended more support for community living for ventilator users. One participant wanted HCP to know that living at home was "not as hard as you guys are trying to make it" (Elizabeth, 870).

Krista spoke of her mother's desire to live at home:

Even her experiences in hospital, for God's sakes, she's not one for enjoying institutional living that's for sure, you know. And, uh, yeah, so I mean the fact that's she's at home on a vent is, oh, yeah, that's definitely good, the most important because, like I said, if she wasn't at home she wouldn't be vented, in my opinion (Krista, 665-670).

Helen wanted HCP to understand that home was often the best place for VAI, and that paid family caregivers often provided the “better” care:

Sometimes your better care comes from your family members. It's not always a bad thing. Family members are probably going to do more things than the ones, the staff that you hire. Because the staff is going to just do what they are told to do. They are not going to do, you know, the little extras . . . as a family member you have a tendency to push your own family member more. You know, get them to do more than a staff member would (Helen, 617-628).

Support for rural communities

Individuals living outside of a major urban centre found it particularly challenging to recruit personal attendants to assist with care:

It's frustrating not having enough people. Whether it's interest in working or available to work. It's worrisome because you don't know if we're short staffed what happens. Where, you know, how long can we double up on shifts and that type of thing. It's an ongoing struggle everywhere though. . . And it's not for everybody. Like we've had some people working that it just, they want to try it. They do, but it's just not meant for them. And, you know, at least, you know, they come and ask and check into it and, you know, learn from there I guess (Helen, 520-533).

One participant used the term ‘perimeteritis’ to describe her perception of a consolidation of services within the city, and her sense that health professionals believed that “life did not go on outside of the city”. Finding knowledgeable health professionals outside of the city was a very trying experience. VAI and caregivers recognized HCP inexperience in many individuals that they encountered.

Ventilator patients, people do have a life. They can have a good life out there and it just needs to be opened up to them. And, well probably one of the barriers that we're talking about is that there's no place for, there's only one place for them to go and that being (name of city). And that, uh, it's almost as if other facilities are too scared to take somebody on a ventilator in. And even though they're nurses and they're doctors, they're therapists, it's like, and well I don't know what to do here. Like I've never dealt with this before (Helen, 697-706).

Annette had been told that she could not move closer to her rural home because “they need to have more trained help [in rural area] (Annette, 1068-1069).

If they had people to look after me, they have a senior home and they have a hospital, like they do have everything [else] (Annette, 948-950).

Health care professional related issues

While participants described positive experiences with health care professionals, one of their major recommendations concerned improving HCP attitudes and level of knowledge of LTMV:

Listen. Listen to them (vent user) with both ears. And with your brain (Les, 836-837).

The hardest part of the whole mechanical ventilation thing is people's attitudes in my experience (Krista, 358-359).

... understand that people are individuals and some people can have quality of life that they enjoy, you know, even with something like ALS or another disease that requires a ventilator and anything else, you know (Krista, 1043-1047).

Be more open minded. Have a more compassionate side to them and to try to understand how a person still feels. They could have quality of life on assisted ventilation. To make sure in the decision making that people have all the facts. I guess that goes along with the whole thing there (Elizabeth, 831-837).

Krista spoke of her experience observing interactions between her mom and HCP:

But, yeah, so I remember saying to her well mom, like didn't you tell me you were going to go on a ventilator, like nobody seems to be talking about that ... she'd say something like, well I plan on you know, living at home. And, you know, I'm going to go on a ventilator and I'm going to have staff and what not. And there was quite a bit of, oh, like right, obvious taken aback by that (Krista, 1092-1094; 1097-1101).

Elizabeth speculated upon possible reasons why HCP were negative about

LTMV:

I suppose there's the old let nature take its course (theory). . . Until I got in this boat, I did not understand either. They really feel that without arms and legs and (the) ability to move around and do things for yourself, well and to breathe on your own, that you just can't have quality. I don't know if they think it costs too much; sometimes I wonder if it's the cost of keeping a person alive on mechanical ventilation that affects their opinions or what. I just really don't know altogether (Elizabeth, 337-347).

Krista described how attitudes were conveyed without words:

So it was definitely a lot of body language. And I believe we even had a head shake once. The dropping of the head, you know, some side head shake, and you know, those types of things (Krista, 1104-1109; 1134-1136).

Rose reflected on the origin of many HCP attitudes. She believed that it was difficult for many HCP to be confronted with individuals who chose to live on LTMV:

They try to protect. I think people are so worried about protecting their own feelings as, as being affected by what they're experiencing. Why what they have to deal with this person that's got the serious illness and it's too scary for them, you know, or whatever. So their way of, you know, they're told that, you know, disconnect from it and that'll protect you. Well maybe that's a quick and easy way of trying to deal with it but it's certainly not a fair solution (Rose, 1676-1684).

Rose wanted HCP to see the person in front of the ventilator. She encouraged HCP to get to know the individual as a person:

It can really make a person feel validated and acknowledged as a human being. Be able to voice how they are feeling about what is happening to them. And not just about the care and about where they're going to be sent or what their options are or that sort of thing. But about what their life was beforehand and, and how do they want to see their selves, how do they see their selves with a new life, you know. And what can they incorporate from their old life into their new (Rose, 178-1189)?

You know, we are people, we are not, you know, like go to the person first and then ask how they're feeling and how this machine is working for them and stuff like that (Margaret, 1335-1338).

Krista believed that her mother's choice to ventilate resulted in stigmatization by some HCP:

And all these people looking at her like she's some sort of messiah because she's chosen to go on a ventilator and feels that she has quality of life (Krista, 571-574)

Participants recommended improving HCP knowledge and experience with LTMV:

They're (HCP) too afraid too. Well there's a fear of, what if I do this wrong with this person (Helen, 711-713).

Usually it's new for everyone involved. And you can't get in a panic if something happens. You have to try and be calm. I have to be calm because if I get in a big fuss, then it's just harder for them to do their job. I think they just get panicky because they know your life is in their hands. But if you just take your time, go through all the things you have learned and been taught, and try and, um, stay calm, things will work out. Especially if there's more than one of you (Elise, 1149-1153; 1167-1172).

Advice for potential ventilator users and family caregivers.

Participants had advice to offer potential ventilator users and their family caregivers.

Ventilator users

Recognizing and responding to symptoms early in the course of illness was emphasized as a potential strategy to enhance choice throughout the process:

If you suspect there's a problem or seem to be having any kind of a problem address the issue with your physician and, you know, mention that you think this could be a possibility . . . had I done that, who knows where it might have gone. May not have made a difference but it, you know, may have extended the time before I needed the trach initially (Meg, 881-888).

Don't wait so long. Do something as early as you suspect there may be a problem. Because I think that the sooner it's addressed, there may be other issues that you can deal with, without having to resort to the trach initially (Meg, 871-875).

Having a positive outlook was of paramount importance to the adjustment to transition to LTMV:

You really, really, really have to have a positive attitude (Elizabeth, 886-887).

But it just becomes sort of second nature. And you don't even; don't even really think about it anymore. It just is what it is. And I think it's just something that, with time, you just get used to. You know I think you have to have a positive outlook (Meg, 596-601).

Proactive acceptance of the need for mechanical ventilation and assistance in the home was recommended:

I would say to them right from the start; don't say no to that assistance if it's offered to you and they think you need it. Because what you are like without it is literally just the opposite of what you're going to be when you've got it, the ventilation system available (Paul, 1270-1274).

Now we've got somebody here with Margaret 24 hours a day. So now that pressure is gone. Now I feel that I can go away to work and I can be reasonably sure that she's in good hands while I'm gone and I don't have to worry about, you know, the ventilator not working. We should have had this kind of assistance right from day one (Bob, 401-405; 525-526).

Pragmatic advice was also provided, such as the value of access to computer technology and a home accessible to the wheelchair and ventilator. In addition, asking questions was stressed:

Don't hesitate to ask questions no matter how stupid they may seem to you. And if a professional makes you feel like you're stupid, then get another professional (Elizabeth, 891-894).

Finally, ventilator users wished to share their perception of the benefits of mechanical ventilation:

Tell the person that is going to be on the ventilator that it is not necessarily going to change their way of life (Molly, 439-441).

It depends who the person would be but basically take one day at a time. Live through it and learn from it. And maybe you learn something new next. It isn't as hard as you thought it would be. And there is help if you need it (Les, 827-830).

You just get used to it. You know, I think you have to have somewhat of a positive outlook. If you think negatively, of course it isn't going to; you're not going to adjust to it quite as quickly like. But I haven't really found it terribly emotionally draining (Meg, 599-604).

Family caregivers

Meg, a ventilator user, expressed empathy for the caregiver:

So I think for them it is, in some ways I think it's harder for them than it is for the person going through it because they're {the vent. user} sort of moving ahead step by step but they're not, their life hasn't really improved any. It's still staying stationary (Meg/Leo, 551-555).

Krista highlighted the benefit of being a family, and a united front in facing adversity or challenge:

I would encourage communication and just the notion of recognizing strength in numbers, you know, and being together and having each other to rely on (Krista, 1226-1228).

Summary

It is clear that participants share many perspectives concerning health system issues. Participant's lived experience of transition was affected by health professionals and health and social system issues. Positive, negative and neutral influences became particularly evident when participant's perspectives were analysed alongside the thematic analyses (see tables 5.1, 6.1). For example, ventilator user's hospital length of stay was described as affecting the transition experience. Protracted hospitalization was revealed as being a factor constraining the ability to "live self". Similarly, protracted hospitalization challenged caregivers as they continued to view life as being on hold, while they bridged the hospital and home world.

Efforts to minimize bureaucratic and operational barriers to home ventilation and the implementation of strategies to facilitate timely access to modified wheelchairs may positively affect the lived experience of transition to LTMV. Further exploration of these, and other issues, will be discussed in chapter eight.

Chapter Conclusion

Chapter seven presented both ventilator user and family caregiver perspectives, and insights regarding HCP and health system issues. Recommendations and advice for individuals living with CRF and families were also detailed.

CHAPTER EIGHT: DISCUSSION OF FINDINGS

Introduction

Chapter eight presents a discussion of the findings of the hermeneutic phenomenological study of the lived experience of transition to LTMV. This chapter is divided into several parts. It begins with a discussion of the concept of transition and an examination of the central themes that emerged through interpretation, in relation to the literature. Following this, the appropriateness of the chosen methodology and methods in exploring the research questions is discussed, and recommendations for nursing practice, education, and research are presented. The chapter concludes with personal reflection.

Discussion

The findings of this study illuminate the everyday lived experiences of ventilator users and family caregivers as they transition to LTMV, thus facilitating an understanding of the meaning of transition. Rose spoke of being ventilated, emphasizing that *“you’re not defined as a human being; by just the things you require medically”* (955). Paul describes his efforts to maintain wholeness within the face of his ongoing technological reliance. *“Your psyche is there to remind you, you know, that you are not just a body, you are a body and a soul”* (1074-1075). Their words resonate throughout this study, and are a reminder that the phenomenon of interest was human experience, whole and in context.

Ventilator users, and caregivers alike, reveal that transition is about so much more than adjustment to a ventilator. Transition concerns being human, and sustaining one’s humanity. For participants in this study, transition to LTMV meant sustaining “self” and sustaining family.

Transition

The findings of this study reveal transition to be a complex and dynamic process, within which a number of physical, mental and spiritual adjustments occur. The main essence of the meaning of the experience was sustaining self and family throughout those many adjustments. For the majority of ventilator users, an important facet of this essence was the reclaiming of a self that had been subsumed within the symptoms of CRF. Inherent within the transition process was a struggle to overcome circumstances that posed a threat to the "self". Those threats included the tyranny of symptoms, the literal threat of death without MV, and the threat to self-determination imposed by the constraints and restrictions of technological reliance, and health and social system issues and barriers. Intertwined within the transition experience was a lived paradox, wherein the technology that had liberated individuals from the tyranny of symptoms, also imposed new restrictions. Caregivers also described the struggle that occurred during their efforts to sustain their family and they too lived a paradox of gratitude for the life sustaining capacity of MV, and frustration and anger at its imposition upon the family's way of being. The findings of this study add to a growing body of literature concerning transition in health and illness and the nature of living with chronic illness.

One participant described respiratory failure as a major event, and transition as a process of "*adjusting to the event and life*". The participant articulated that "*the main transition was to get back on track in what I felt was my life, you know*" (Rose, 1243). The literature describing the universal properties of transition highlights the importance of the internal processes that accompany physical change or events. It is those internal

processes that facilitate movement through transition periods (Chick & Meleis, 1986; Davies, 2005; Kralik, 2002; Meleis et al., 2000; Schumacher & Meleis, 1994).

Internal processes were illuminated by participants in this study, and were revealed to be a means of integrating major technology into their way of being. Significant personal work was carried out by both caregivers and ventilator users. Caregivers spoke of coaching themselves through exhausting and difficult times, and they discussed the mental processes that had helped them to manage their fears and frustrations concerning the ventilator. Ventilator users described how they thought about being close to death and how they worked to integrate new restrictions into their way of being, so that they could sustain "self". The perspective that ultimately facilitated the view of life going on was predicated upon many of those internal processes. This finding validates the notion that transition to LTMV is a highly complex and personal process, and underscores the need for health professionals to acquire an understanding of lived experience in order to care for individuals and families as they integrate technology into their way of being. It raises questions as to how nurses and others may best support both the physical and internal struggles encountered during transition.

Meleis et al., (2000) analysed several studies of lived experience utilizing a transition framework. They found that many transitions occur simultaneously, which resonates with this present study, as all participants experienced multiple transitions including: health, developmental, educational, occupational, financial, relationship, and others transitions during their time of adjustment to LTMV. This was not surprising, given that transition to LTMV took a very long time, years for some participants.

The transition process was not the same for every participant and the timing for adjustment and adaptation was not identical. The literature concerning transition theory identifies that nurses, and others, who gain an understanding of the universal properties of transition, may be better able to assist those individuals who experience particular difficulty (Schumacher & Meleis, 1994; Shaul, 1997).

One of 11 ventilated participants in this study viewed being mechanically ventilated as just another event that had occurred, and which was symbolic of living life with chronic illness and the experience of multiple complications. He indicated that being ventilated was:

Just another thing to get used to. For me, it was more, it was more of a downward health spiral, more of a step backwards as far as another thing going wrong or adding to, to the list of health concerns or events (Adam, 1026-1028) .

Paterson's (2001) shifting perspectives model of chronic illness may assist in understanding how individuals, like Adam, live the experience of transition to LTMV within the context of the meaning of their pre-existing chronic illness. She carried out a metasynthesis of 292 qualitative research studies concerning aspects of living with chronic illness, and challenged the notion that individuals predictably move through stages or trajectories as they live their life with chronic illness. In the shifting perspectives model, chronic illness is seen to encompass elements of both illness, and wellness, and individuals develop perspective about those elements through beliefs, perceptions, expectations, attitudes and experience about what it means to be a person with a chronic illness. Perspectives of illness and wellness shift from the foreground to the background in the lives of individuals (p. 23).

Paterson (2001) asserts that the major factor that has been identified as shifting a perspective from wellness in the foreground, to illness in the foreground, is the perception of a threat to control. Such threats are personally defined and “may go unnoticed by the observer” (p. 24). This study revealed that those participants who moved to a LTC facility continued to experience a struggle to sustain “self” long after their initial adjustment to ventilation. Such struggle may be characterized as a threat to control as described by Paterson, and may go a long way to explaining how Adam perceived his life. Longitudinal study may better illuminate the specific issues and complexities that occur at varying stages of transition, including when individuals move into a long-term care facility. In addition, further exploration of the interrelationship between transition experience, and pre-existing disease is warranted. These findings reinforce the need for professionals to have knowledge of transition and lived experience in order to assist in identifying individuals at risk for a difficult transition.

Major components of Chick and Meleis’s (1986) nursing model include: process, awareness, perception, disconnectedness, health outcomes and patterns of response (1986). Their relevance to the findings of this study will be discussed.

Process

As identified earlier, this study supports the notion of transition being a complex and dynamic process. However, the view of a definitive endpoint, as described in Chick and Meleis’s (1986) early work, was not born out. As with other studies of transition, participants described open-endedness to their experience of transition to ventilation. (Kralik, 2002; Meleis et al., 2000; Neil & Barrell, 1998; Paterson, 2001; Shaul, 1997). This was particularly true for individuals who had been ventilated for many years.

Ventilator technology is constantly evolving, thus participants continued to experience new adjustments to new technology, across time. In addition, social support structures for independent living were subject to change, and those changes had dramatic (positive or negative) effects on the lives of VAI and their families. Factors that contributed to a sense of open-endedness included: the progression of each participant's underlying disease process, the potential for the development of complications, the possibility of requiring greater ventilator support in the future, and the experience of re-hospitalization. Despite such open-endedness, health professionals should recognize that individuals and families who transition to LTMV can and should achieve a sense of stability.

Awareness and perception

Two participants, who commenced mechanical ventilation on a non-emergent basis, spoke of gaining an awareness of mechanical ventilation in a variety of ways. One participant used computer searching skills to acquire an understanding of both her primary disease and the potential role of MV. The second participant was familiar with others, who had utilized MV.

A third participant had researched her underlying disease for a biology project, thus she indicated having some awareness of the potential for respiratory failure and death; however, she did not have a similar awareness of mechanical ventilation. Therefore, she entered into her transition experience without full awareness of her options.

Most participants in this study lacked an understanding of their underlying disease, in terms of its potential impact on their respiratory capacity. Thus, their

awareness of transition often occurred in the face of respiratory crisis. This had a significant impact upon the personal meaning assigned to the living of transition. Participants commenced transition believing that they really had no choice. Those few participants with a better understanding of their disease, and the respiratory risk it conferred, had a greater awareness of transition and benefited by experiencing proactive preparation and decision making.

Disconnectedness

Disconnectedness is characterized by instability and is a time of uncertainty, ambiguity, adjustment and adaptation to change. Change incorporates psychological, physical, social and economic dimensions (Chick & Meleis, 1986). As change occurs, a new self-identity develops (Shaul, 1997). Ventilated participants in this study revealed their experience of being disconnected as one in which they struggled, both physically and psychologically, with the adjustment to being mechanically ventilated. During the period of disconnectedness, participants adapted to an altered body; and a new way of breathing, eating and communicating. Some participants withdrew from friends, family and HCP, eventually reconnecting with others. While participants did incorporate ventilator dependence into their self-identity; this study revealed their additional and meaningful quest was to sustain "self", and family within the context of technological reliance.

Caregivers revealed that disconnectedness was particularly prominent when their family member was initially hospitalized in the ICU, and then again when they returned home or moved into a LTC facility.

Patterns of response

Patterns of response take into consideration the unique aspects of each individual who is undergoing a transition. Responses are influenced by contextual, situational, and biological factors (Chick & Meleis, 1986). In this present study, individual patterns of response were significant factors in the individual meanings that were attributed to the experience of transition to LTMV. Several individuals had experienced a lifetime of functional, and mobility issues, in addition to adjustment to living with chronic illness. Others experienced transition to LTMV within the context of absorbing the meaning of a new diagnosis, such as ALS, or quadriplegia. Social support was variable for participants, and several revealed experiencing the loss of their primary relationship during their transition to LTMV.

Psychological factors such as hardiness, locus of control, tolerance of uncertainty, and problem solving capacities have been described as affecting transition experiences (Chick & Meleis, 1986). This study revealed the importance of psychological factors in assigning personal meaning to lived experience. Many of the participants' description of self-advocacy reveal their ability to take personal control within the context of a situation of potential vulnerability. Most participants also describe significant perseverance and this assisted their ability to reside in the community. However, other participants seemed weary of both their chronic illness and the repetitive requirement for self-advocacy. Locus of control, and the ability to relinquish internal control, appeared to assist those who were required to reside in a LTC facility. For example, one individual, who resided in a LTC facility, viewed health professionals as being helpful, while another participant viewed the same personnel as being oppressive and intrusive. Overall, personal meaning played a significant role in each of the participant's lived experience.

Discussion of themes

The following section will discuss many of the themes that characterized participants' experience of transition to LTMV. They will be examined within the context of the conceptual framework of transition and the shifting perspectives model of chronic illness (Chick & Meleis, 1986; Kralik, 2002; Meleis et al., 2000; Paterson, 2001). The examination will highlight risks and vulnerability to participant wellbeing in an effort to provide context for the subsequent presentation of implications and recommendations for practice, research and education. In this way, I hope to illustrate how gaining an in-depth understanding of lived experience provides a meaningful conduit for quality improvement, holism and excellence in nursing.

Tyranny of symptoms/Intrusion of symptoms

Experiencing symptoms

The lives of participants in this study were adversely affected by the manifestation of symptoms of CRF. Through retrospection they were able to provide rich and detailed description of the tyrannical nature of their symptom experience. Even though symptom manifestation and distress has been well described for a number of diseases, including cancer, and acute and chronic obstructive respiratory conditions (Caroci & Lareau 2004; Hofman, Ryan, Figueroa-Moseley, Pascal & Morrow, 2007; Honea, Brant & Beck, 2007), to date the living of the symptom experience in chronic respiratory failure has not been well detailed. This despite the fact that research has shown that symptoms can have a dramatic impact on the ill individual's sense of self as well as the sense of self of individual family members (Woodgate, 2001, 2005). In a study of childhood cancer, adolescents with cancer revealed that although they faced many challenges because of

cancer, most significant to them were the distress and suffering that originated from the symptoms. The symptoms resulted in the adolescents experiencing new physical and mental bodily changes throughout the cancer trajectory. Moreover, their perceptions varied from them viewing themselves to be almost the “same old self” to feeling almost like a completely different individual (Woodgate, 2001, 2005).

The lived experience of symptoms of CRF are briefly described in a qualitative study by Lindahl et al. (2005) that explores the meaning of becoming dependent on home mechanical ventilation. The authors interviewed 13 nocturnally ventilated participants, three of whom were diagnosed with obesity-hypoventilation syndrome. Nine participants were non- invasively ventilated. Similar to this present study of transition to LTMV, the authors describe the symptoms of CRF as living a “half-life”. However, they also describe mechanical ventilation as an unburdening and a release from dyspnea.

In this present study, symptoms of fatigue, loss of energy and cognitive capacity were revealed to have dominated participants’ existence prior to LTMV. Shortness of breath was mentioned by only two participants in this study. Often individuals with neuromuscular disease and chronic respiratory insufficiency do not experience shortness of breath (Robert, as cited in Lurie, 1999). In addition, in contrast to the study by Lindahl et al. (2005) all of the participants in this study were invasively ventilated, and many had commenced ventilation on an emergency basis, thus it is likely that they had more progressive disease.

Symptom Distress

This study describes how participants lived the symptoms of CRF, and in so doing it highlights the uniqueness and significance of their experience. It brings a voice to the

distress as it was lived. Symptom distress differs from symptom occurrence in that it refers to an emotional response to the symptom. Distress is protective in that it normally motivates an individual to take action in order to alleviate their suffering (Fu, McDaniel, & Rhodes, 2007).

Significantly, in this study the insidious and progressive manifestation of symptoms was not always accompanied by distress. The psychological response to symptoms was often described in retrospect, when participants' energy and cognitive capacity were restored by MV. There was a passive, almost sinister nature to symptom development because as symptoms worsened, the participant's capacity and motivation to seek assistance waned. Headaches were the only physically painful symptom described; therefore, those distressed by them were more likely to independently seek assistance. Family, friends or co-workers, who witnessed the individual with CRF "fade away", often experienced distress, thus their alarm served to motivate individuals to seek assistance.

Three factors played a critical role in the prolongation of symptom experience:

(1) Absence of contemporaneous symptom distress; (2) encounters with health care professionals that did not result in proactive consultation, diagnostic evaluation or symptom management; and (3) most participants were unaware that their disease conferred a risk for respiratory failure. As a result, several participants experienced respiratory crisis, which necessitated emergent intervention.

In a review of non-invasive ventilation for chest wall and neuromuscular disorders, Shneerson and Simonds (2002) emphasize the need for early identification of patients so that they can be "warned of symptoms suggesting nocturnal hypoventilation"

(p.481). They highlight the need for long-term follow-up, describing the onset of ventilatory failure as insidious. The findings in this present study of transition support the notion of symptoms developing insidiously, yet it should be emphasized that the cumulative effect of symptoms was evident. Meaningful interaction with knowledgeable professionals, and timely intervention, may have altered the course of participants' symptom experience.

The necessity for emergency respiratory management played a significant role in the way that transition unfolded for participants. Respiratory crisis, necessitating hospitalization, was accompanied by marked deterioration in mental status, which manifest in hallucinations, paranoia, decreased levels of consciousness and a compromised ability to engage in meaningful decision-making activities. Family and caregiver distress were also heightened. Furthermore, the opportunity for participants to effectively utilize non-invasive forms of ventilation may have been compromised.

Several studies have explored morbidity and mortality in relation to the timing of initiation of MV. In particular, there is a proliferation of studies exploring the timing for introduction of NIMV (Nava, Navalesi, & Conti, 2006). Other studies have identified issues with the timing of initial ventilation as relates to ventilator user perspectives (Brooks et al., 2004; Goldstein et al., 1995; Lindahl et al., 2005). This study provides an in-depth description of how individuals and families live the consequences of a lack of proactive assessment and intervention. Timing may affect a variety of aspects of lived experience including: (1) perception of meaningful choice; (2) location for commencement of ventilation (in-patient versus out-patient); (3) the need for an emergent, and often traumatic ICU admission; (4) the need for invasive ventilation; (5)

the mental state and level of consciousness at time of intervention; (6) hospital length of stay; and (7) caregiver distress.

This study revealed that the lived experience of transition to LTMV was highly affected by health professionals' attitudes and the manner in which they communicated with individuals living with CRF. Participants, who were informed of ventilation prior to respiratory crisis, sometimes described experiencing a sense of stigma and a lack of collaboration during the commencement of ventilation. They described an overwhelming pessimism on the part of many health care providers, and expressed a longing for health professionals to offer them hope that they could still have a life.

A review of ethics and decision making in end stage lung disease (Simonds, 2003a) identifies health provider perceptions of poor QOL as an influencing factor in their communication of options for MV. In this present study, several ventilator user and family caregiver participants disclosed how they experienced communication with health professionals who appeared to question their choice for ventilation. They described the need for tremendous self-advocacy and their engagement in a process targeted to convincing or influencing health professionals' perception of their choice.

These findings highlight the need for primary health care providers to acquire a greater understanding of the population at risk for CRF and the insidious nature of their symptom experience. Health professionals need to understand that many individuals with CRF lack sufficient symptom distress and energy to be alarmed by their symptoms; nonetheless symptoms have a highly deleterious impact on both the individual with CRF and their family. Meaningful involvement of significant others is essential as they are often the ones most able to identify symptom progression.

Self in peril/Being there

Recognition of having been close to death, and choosing between death, and being mechanically ventilated, affected the meaning that both ventilated individuals and family caregivers attribute to living the experience of transition. Participants often felt as though they really had no choice, which meant only having the choice between being ventilated or dying. Similarly, in a study of 38 VAI aged six years to 66 years, and 43 family members, the younger participants were reported to especially feel as though they really had no choice regarding being ventilated, remarking, “you don’t want to die do you?” (van Kesteren et al., 2001, p.443). In another study of technology-dependent individuals, nearly all 18 long time dialysis survivor participants reported making a conscious ongoing decision to live, and their decision was supported with continuing affirmations such as: “I want to live, I am still me, and I am still valuable” (Curtin, Mapes, Petillo, & Oberley, 2002, p. 613).

In this present study, many participants revealed their perception of having made a decision about life-long ventilation while in the ICU. They reveal traumatic and very distressing memories of their time in the ICU. Interventions such as intubation, and the insertion of invasive lines sometimes occurred without participant understanding and often within the context of an altered mental state and ability to communicate. This was distressing for both the ventilator user and the family caregiver.

Caregivers recalled being present as their loved one was being asked to make a “life-or-death” decision. They revealed that “being there” during that time was the source of significant anguish. Many caregivers perceived that the decision about tracheotomy and ventilation could not be their decision to make.

Happ, Swigart, Tate, Hoffman & Arnold (2007) explored decision-making during prolonged critical illness to elucidate if, and how, patients are involved. They report that health professionals initiate and maintain communication with patients, even when there is cognitive impairment or an altered state of consciousness. In their study, patients only initiated communication when refusing treatment or a specific intervention. Overall, communication was seen as a negotiated process shared between family, patient and health professionals. This would appear to have been the case in this present study as well.

However, this study also highlights the lived burden of decision making, as described by the family caregiver. Because decision-making often occurred within the context of their loved one's altered mental state and compromised ability to communicate, caregivers experienced angst about the way that the decision-making process unfolded. In retrospect, all participants believed that the right decision had been made. However, the final decision was not the only factor influencing participants' perspectives. The "how and when" of decision-making was revealed to be critical to the participants' subsequent experience of transition and their perception of choice.

Reasons why participants were not provided with more proactive management of their respiratory risk are not clear; however, the consequences, as lived by ventilated individuals and families were described. Simond's (2003a) review of ethics, and decision-making in progressive neuromuscular disease describes MV as being both beneficent, in that it prolongs life with acceptable self-reported QOL, and maleficent in terms of diminishing privacy, imposing burdens, and causing distress (p.275). Within that context, she discusses the need for physicians to balance the principles of autonomy,

beneficence, non-maleficence and distributive justice. She asserts that physicians require current knowledge and understanding of treatment options with respect to ventilation. She emphasizes that decision-making can not occur in a fully informed manner if information about ventilator treatment options is withheld. She suggests avoiding unilateral decisions, based on the perception of poor quality of life, citing the growing body of evidence that physicians, and other health professionals, consistently underestimate QOL for individuals living with neuromuscular disease (Bach & Barnett, 1994; Bach, Campagnolo & Hoeman 1991, as cited in Simonds, 2003a; Gibson, 2001)

Further study exploring how the principles of autonomy, beneficence, non-maleficence and distributive justice are balanced for this population is warranted. What are the factors that particularly influence how those principles are balanced? In addition, further research specific to decision making is warranted: How do health professionals conceptualize decision making within the context of an altered mental state? What does the burden of decision making mean to caregivers in the short and long term?

Communication

In this present study of transition to LTMV, communication issues were revealed to be a significant challenge to all ventilated participants. Participants described feeling frustrated, vulnerable and alienated during their time in the ICU, and they utilized significant energy in order to communicate. Family caregivers described feelings of inadequacy, helplessness and frustration, and they wondered about the future and whether their family member would ever be able to talk.

Communication and MV has been studied using both qualitative and quantitative methodologies (Chlan, 2003; Johnson, 2004; Menzel, 1998; Patak, Gawlinski, Fung,

Doering & Berg, 2004; Wojnicki-Johansson, 2001; Wunderlich, Perry, Lavin & Katz 1999). Taken in total, these studies establish communication difficulties as being a significant source of ongoing suffering for the ICU patient and their family.

Several participants in this study described their experience of an altered mental state and caregivers expressed the anguish they experienced in trying to communicate with their family member as they were hallucinating, delirious or paranoid. Some ventilated participants spoke of withdrawing from others during their ICU experience. Hafsteindottir's (1996) phenomenological study described the tendency for patients to respond to communication challenges by withdrawing and become apathetic.

The literature concerning the ICU and MV has explored a variety of strategies to assist with communication, including: writing, gesturing, eye blinks, touch/pointing with word or picture boards, and lip reading (Happ, 2001). Several participants in this present study described the efforts made by nurses and others to assist with communication. Note writing was frequently described, but it was not always regarded as an effective strategy as participants were often tremulous in the early days of their ICU admission. However, the ability of the nurse to read lips and to direct conversation in order to allow for "yes" or "no" responses was viewed as being most effective. The caregiver and the ventilator user often spoke of communication within the context of the "busyness" of the ICU or IICU environment. They emphasized that communication took time, and that the ICU was a busy place and the nurse was seen to be "a busy person". Studies have characterized nurse-patient communication in the ICU as being short and task-related (Ashworth, as cited in Happ, 2001; Fitch, Remus, & Stade, 1998). Furthermore, research has revealed that communication with family is more likely to be targeted to explaining

equipment and procedures rather than the assessment of family coping (Fox & Jeffrey, 1997).

In this study, a participant described being admitted into an ICU and the communication challenges that contributed to her feeling of being traumatized:

Are you crazy? It's like, OK, OK, wait, wait. I just wish they would give you a chance to have a breather in between, between things. And then you can't say anything. It's like more traumatic than anything (Rose, 351-352).

A meta-analysis of non-vocal ventilated patients' perceptions of being understood found that misunderstandings, altered perceptions, inequality of communication, loss of control, negative emotions, dependency, unmet needs and dehumanization characterized much of the ICU patients' experience. Participants expressed appreciation when the nurse represented a caring presence and they also "acutely perceived whether the nurse cared or not, and this affected the trust placed in that nurse" (Viner, as cited in Carrol, 2004, p.97). Studies suggest that nurses primarily affect the mechanically ventilated patient's experience of communication in the ICU (Johnson, 2004; Russell, 1999; Seeger-Jablonski, 1994). Nursing interventions that convey caring, empathy, reassurance and validation, have been reported to positively affect patient's ICU experiences (Hafsteinndottir, 1996; Johnson, 2004; Seeger-Jablonski, 1994; Wojnicki-Johansson, 2001).

Strategies to facilitate speech are available to the ventilated patient, once they become stable (Happ, 2001; Hess, 2005). Although the process of regaining speech is a difficult one, which requires significant effort on the part of the patient, this study illuminated the significance of communication for both the VAI and the family. The timely implementation of current methods to assist with communication are essential and

may assist ventilated individuals and caregivers in their effort to sustain self and family as they transition to LTMV.

Awakening to a paradox/ Bridging two worlds

Previous studies have identified that living life reliant on technology is a life lived within a paradox of freedom and constraint (Lehoux et al. 2004). People reliant on technology report a similar paradoxical experience regardless of the type of technology that is implemented. The utilization of home parental nutrition and the reliance upon dialysis, oxygen, tracheotomy or a mechanical ventilator impart the same paradox, and a similar need for individuals to coalesce their sense of restriction with their sense of freedom (Braun Curtin et al., 2002; Lindahl, 2005; Martin-McDonald, 2003; Winkler et al., 2006). The living of the paradox has been described as continuing across time (Lehoux, 2004; Lutz & Bowers, 2005).

The participants in this present study awakened to a paradox in that the restrictions imposed by being ventilated became apparent within the context of their experience of renewed energy and vigour. Consequently, participants often used their improved energy and cognitive capacity to grieve loss. In three instances, the loss that was grieved was that of their primary relationship. Ventilator users described the challenge that family members faced as they worked to bridge the home world and the hospital world. For some family members, the ongoing challenge proved too difficult, thus ventilator users were left with a significant loss and yet another transition in their life. Other participants lost their primary residence in the community, or their prior employment or role within their family.

Making a case

Participants also recognized that they had energy that had been eluding them for years. Ultimately, most participants moved through their experience of awakening to a paradox by focusing on those restrictions that they perceived to be most within their control. They worked to make a case for their right to self-determination. This finding is echoed in Johnson's (2004) phenomenological study of the meaning attributed to being mechanically ventilated in the ICU. Critically-ill participants in that study moved from discontinuity and questioning survival to re-engagement with staff and families. The author describes participants' attempts to communicate and seek control over treatments as a process of reclaiming the everyday world that had been lost when they were hospitalized in the ICU.

Paterson's (2001) shifting perspectives model of chronic illness describes a threat to one's control as being the most significant factor in moving illness into the foreground of one's life. This is consistent with the findings of this study. Participants worked hard to stave off the threat to autonomy that seemed to be inherent in "being ventilated". In Charmaz's (1983) influential work on living life with serious chronic illness, she identified that living with chronic illness, with or without reliance upon technology, was a threat to self. In a qualitative study of 57 chronically-ill individuals, Charmaz found that the living of a restricted life led to social isolation, which in turn led to diminished opportunities to positively validate self. In this present study, participants lived a restricted life that was imposed by hospitalization. In order to sustain self, they needed to prove that they could leave the hospital, or continue to work, or study, or live at home.

An important question is whether those individuals, who are less successful in making a case for themselves, or who do not have family or others to bolster their case,

are more prone to living their chronic illness experience with illness in the foreground? Lehoux et al. (2004) assert that technology can provide autonomy; however this is often contingent upon the assistance or involvement of others, thus those who are more successful in mobilising resources are more likely to gain control of their life.

As ventilated individuals awakened to renewed energy, and began to make a case for their future, caregivers continued to travel back and forth between the hospital and their home. Caregivers bridged the home and hospital world for months to years. They often continued to work and maintain their home, and as they did, they became weary and frustrated. They too were required to make a case for their ability to assist their family member.

Struggling for autonomy/Making peace with the ventilator

The participants in this study were required to make a case that they could live at home. They described significant efforts to convince the health system that they were capable of doing so. For individuals without committed family caregivers, or those living in rural environments, the task was particularly difficult.

The focus on making a case motivated many participants to look ahead to their future, and their success in making a case often resulted in a feeling of pride that they had convinced HCP of their abilities and helped HCP to know them as a person. For others, there was a sense of being wounded by the health system, particularly if they had also been required to make a case in order to be ventilated in the first place.

Nurses and respiratory therapists were sometimes described as assisting with the process of making a case. One participant spoke of her significant struggle to convince her physician that she should be ventilated. In the end, she describes the physician as “the

one” who advocated on her behalf to other health professionals. Participants often spoke of the “one individual” who provided them with hope or who championed their case. Such champions were important to their cause; however, such support also assisted the VAI in integrating technology into their way of being. Lutz and Bowers (2005) explored how individuals with chronic illness and disability live their everyday life. The authors report that the perceptions and influence of family, friends and health care providers were pivotal determinants of their ability to successfully integrate disability into their lives (p. 1045).

The literature concerning living life with a chronic illness describes the important role of self-advocacy. The QOL for individuals living life with chronic illness depends significantly upon their ability to provide or direct self-care and to develop decision-making skills (Thorne et al., 2000). Thus, it stands to reason that those particular skills should be encouraged and respected by health professionals. For participants in this study, their long hospital stay proved to be a particular challenge to the development and reinforcement of such skills.

The research indicates that the length of initial hospital stay for long-term ventilator users is highly predicated on an integrated in-patient/out-patient system of care and a high degree of interdisciplinary and inter-sectoral collaboration (Bowers, Esmond, Lutz & Jacobson, 2003; Kopacz & Moriarty-Wright, 1984; Montgomery & Friss Feinberg, 2003; Thompson & Richmond, 1990). The “waiting” to be discharged from hospital became particularly meaningful for both ventilator users and caregivers. Virtually every participant believed that they were in the hospital beyond the time that was medically necessary. Some participant’s spoke of this as being a very real threat to

“self”. The literature on ventilator dependence in children explores the issue of prolonged periods in ICU and the hospital. Noyes (2000) describes detrimental effects on the social and developmental performance of the child and the overall healthy functioning of the family.

The participants in this study of transition identify similar difficulties in their ability to be a family. Caregivers experienced role change, while ventilator users continued to feel limited, confined and somewhat oppressed. Caregivers began to feel more included and hopeful when they received extensive education concerning the ventilator and the tracheotomy. However, as they began to understand the machine, they experienced fear, but they also began to develop a sense that they would be able to assist. In due course, fear of the machine was coalesced with gratitude for the life of their loved one. Ultimately, they came to a kind of peace with “the machine”. Leo explains:

It doesn't make a difference in our life because she's on a ventilator. Just makes a difference in our life because she's here (Leo, 1045-1051).

Life goes on with a reclaimed self/Life goes on with a new vigilance

Both ventilator users and their family caregivers describe their gratitude for the technology that is the ventilator or “the machine”. Absent major symptoms of CRF, ventilated individuals view life as going on, often with a renewed energy. However there was open-endedness in their perception of transition. This finding is echoed in a study exploring the cancer symptom experience of children and families (Woodgate, 2001). Participants in that study made the distinction of having gotten “through”, rather than “over” their cancer experience. Such a life-altering experience was deemed to continue to be with the individual throughout their life.

Caregivers also integrated technology into their way of being a family, but they revealed being on a different time table than the ventilated family member, who had been with “the machine” for months to years. Meg describes her empathy for the role of the caregiver:

So I think for them [family caregivers] it is, in some ways harder for them than it is for the person [VAI] going through it because they're {the vent. user} sort of moving ahead step by step but they're [the caregivers] not, their life hasn't really improved any. It's still staying stationary (Meg/Leo, 551-555).

The homecoming was revealed to be exciting, nerve-racking and difficult. There were many adjustments to make. Lehoux et al. (2004) describes medical technology as transforming the meaning of home for all family members. Technology imposes new roles and ways of being. In this study, family caregivers struggled with a new proximity to the VAI, which also meant a more intimate understanding of their world. Family members described a process of adjustment that took a good deal of time.

Nurses and respiratory therapists were valued for their ability to provide information, encouragement and positive reinforcement. Caregivers were grateful for opportunities to meet with the nurse in their home or to know that they were readily available on the phone. Eventually caregivers developed confidence. Their life was somewhat narrower than it had been, and they had to work hard to plan ahead for activities. Ultimately they began to believe that “life goes on”. However, the technology that supported breathing could not be dismissed and caregivers lived with a relentless sense of fear.

Summary

The previous discussion of findings highlights many areas where ventilated individuals and family caregivers are particularly vulnerable to experiencing difficulty

with transition. If the goal of transition is to support individuals in making the physical, spiritual and psychological adjustments necessary to successfully integrate ventilator technology into their way of being, then an understanding of their lived experience is essential.

Discussion of SF12v2 Health Survey Results

The SF-12 health survey results confirm the findings of prior studies of home ventilator users. Despite very low physical functioning scores, VAI rate their health status equal to, or better than those living with other chronic illnesses such as diabetes, heart failure or chronic kidney disease (Bach et al, 1991; Simonds & Elliot, 1995; Windisch, 2003b).

The MCS scores of five of seven caregiver-VAI dyads are of interest in that they indicate that caregivers may experience mental distress. This finding has also come to light in previous studies, and suggests the need for further study in a larger population. Recognition that caregivers may be particularly vulnerable to emotional distress is an important first step in the development of interventions targeted to minimizing distress.

Studies utilizing a variety of tools have measured high levels of stress, strain, and depression in caregivers (Cannuscio et al., 2002; Ferrario et al., 2001; Hirst, 2005; Im et al., 2004). The qualitative findings of this study describe the transition experience from the caregiver's perspective, and highlight a number of potential areas of vulnerability:

- a) Caregivers expressed concern regarding the intrusion of symptoms on the family's way of being, and they were distressed by their effect on the individual with CRF.

- b) The lack of early diagnostic evaluation and intervention meant that caregivers were eventually thrown into a crisis situation where they experienced distress.
- c) The life-or-death decision-making experience was described as a particular burden for caregivers and their difficulty in communicating with the ventilator user compounded their anguish.
- d) The long period of hospitalization weighed heavily on the caregiver as they became exhausted, frustrated and lived a “tentative life” or a life of uncertainty.
- e) Caregivers were also required to advocate for their loved one and their right to self-determination, and as they learned about the ventilator and all that could go wrong, they revealed having longed for a positive attitude and some hope about the future.
- f) In the end, caregivers revealed that they experienced a pervasive fear that something might go wrong with the ventilator.
- g) They maintained an ongoing vigilance.

It should be noted that, as with other studies of caregiving, participants in this study also describe a lived paradox of burden and fulfilment (Berg-Weger, 2001; Butcher & Buckwalter, 2002). Caregivers outlined areas where they believed that the health and social system could improve in their care of ventilated individuals. Further longitudinal, descriptive, exploratory study of caregivers is warranted. Recent studies have begun to explore whether enhanced educational or community resources diminish caregiver stress.

Discussion of Chosen Methodology

Only people with chronic respiratory failure who transition to a life of reliance on LTMV know what that experience is like. In this study the questions that I posed

concerned their human experience. What is it to transition to LTMV? What is it like to be a family caregiver of an individual who has transitioned to LTMV? What are the similarities and differences in the meaning of the experience for caregivers and ventilator users? These questions are the concern of human science.

Thus constructivist/interpretive methodology, and phenomenology in particular, were appropriate for this study. The methodology served as a kind of scaffolding, or the philosophical foundational structure around which this study was designed. The methodology provided continuity and cohesion to the study from its inception through to the discussion of findings, thus facilitating the illumination of the living of transition to LTMV.

The methodology informed the methods of this study. Sampling plan and size, data collection strategies, and methods for analysis were developed with the goal of explicating a rich and detailed description of the transition experience as it was lived. An ontological, hermeneutic perspective facilitated my way of being with participants' words and stories, which ultimately became rich and meaningful data. Van Manen's (1990) method for data analysis provided a way of thinking about the data and being with the data; so that the meaning of participants lived experience could be described.

The quantitative tool (SF12v2 questionnaire) generated a snapshot of the participants' perspectives of their health at the time of the interview. The survey tool proved to be brief, thus minimizing participant burden and findings allowed for an interesting comparison with the "normed" population and others living with chronic illness.

Study Limitations

Several limitations warrant consideration. As with any qualitative study, the findings of this study are not meant to be generalized to all individuals who experience transition to LTMV. Additionally, the retrospective approach of phenomenological research can raise questions as to the accuracy of participant's recollection of unfolding events. However, this phenomenological study concerns individuals' perspectives, which are human constructions and provide the basis for thematic analysis of narrative text.

The SF-12 findings were generated by a small sample size; therefore, they are not statistically significant. However the results highlight areas for future study, particularly of caregiver-ventilator user dyads. In this study, participant scores were compared with published US norms. While Canadian normative data was not available for the SF-12 survey, such data has been produced for the SF-36 health survey. When compared with US scores, a pattern of higher scores for all domains and summary scales was seen (Hopman et al., 2000). This should be taken into consideration when reviewing the SF-12 findings of this study.

This study would have been enhanced by the participation of individuals who utilized NIV strategies, as the prevalence of NIV has increased dramatically over the last decade. No participant who utilized such strategies volunteered to participate in this study. As previously mentioned, female ventilator users were overrepresented in this study sample. In addition, only one family caregiver, whose family member resided in a LTC facility, was represented.

The findings of this study illuminate shared experience, thus providing a path for future research in this population. Additionally, the findings from this study may serve to help clinicians understand the complex phenomenon of transition and reliance on

respiratory technology, affording them new insights into the perspectives of their patients.

Recommendations

In the following section I will discuss the findings of this study in relation to their implication for nursing practice, education and research.

Recommendations for Practice

Despite the fact that nurses care for individuals living with CRF, their opportunities to understand how individuals and families experience transition to LTMV is limited. Moreover, their understanding of the meaning of reliance upon technology is not always based on a depth of understanding of their patient's perspectives. Thus, one of the goals of this research project was to develop a rich depth of description of the transition experience as it was lived so that nurses, and other health professionals, may begin to understand the insider or "emic" perspectives of individuals in their care.

The findings of this study reveal a wealth of potential areas of interest to nursing. However, my initial focus, in terms of implications for nursing practice, primarily concerns "understanding" and coming to know what it may be like to experience the phenomenon of transition to LTMV. In my earlier assumptions, I described how nurses identify the care of individuals transitioning to LTMV as emotionally draining. It is significant that nurses use the words "emotionally draining", rather than technologically demanding or time-consuming.

One of the participants in this study spoke about nurses and stated the following:

They try to protect. I think people are so worried about protecting their own feelings as, as being affected by what they're experiencing. By what they have to deal with; this person that's got the serious illness and it's too scary for them. So their way of, you know, they're told that, you know, disconnect from it and that'll

protect you. Well maybe that's a quick and easy way of trying to deal with it but it's certainly not a fair solution (Rose, 1676-1684).

Younger (1995), writes of the phenomenon of turning away from one who suffers. She describes "the alienation of the sufferer; one of the great paradoxes of human existence" (p.53). Suffering is described as having the capacity to destroy one's ability to communicate. She explains that suffering patients are unable to explain what is happening to them, when it is happening to them. Thus it seems clear that studies providing individuals with an opportunity for reflection may best elucidate the nature of their suffering.

Kuhl's (2005) qualitative study explored spiritual and psychological issues at the end of life. He described "iatrogenic suffering", or the suffering that is imparted on patients by the very system and health providers who are there to assist them. He also suggested the possibility that professional health providers, in the following case the providers were physicians, may also suffer. "The moment when patients experience the greatest psychological and spiritual need might be the moment for which physicians have the least training. The patient can experience iatrogenic suffering; perhaps the care provider suffers as well" (p. 1607). In this study, Rose described the suffering she experienced when nurses "disconnected" from her in a time of need. Perhaps, as Kuhl postulates, nurses caring for Rose also suffered.

As discussed in earlier chapters, health professionals consistently underestimate the QOL of long-term ventilator users. That being the case, it is perhaps not surprising that the act of being with and caring for an individual, as they struggle with the complex process of transition to LTMV, may be a particularly daunting experience. When nurses stand within their patient's world of struggle and suffering, they need to know that the

overall essence and meaning of their client's experience is not one of suffering, but one of hope. Moreover, they need to be aware of how they can facilitate hope and assist them through transition.

Kingsbury (2000), a professor of clinical psychiatry who has multiple sclerosis, contends that the mistake many health professionals make is in viewing illness from their perspective rather than that of the patient. He encourages health professionals to remember that illness is only a minor part of a person's identity. He also asserts that most individuals living with chronic illness "do not require psychiatric help, although [health professional] patience and understanding are always appreciated" (p. 4).

Dissemination of the findings of this study may begin to assist nurses and others in developing that "appreciated understanding" of their client's experience of transition to LTMV. "Phenomenological knowledge reforms understanding, it does something to us, it affects us, and it leads to more thoughtful action" (Van der Zalm & Bergum, 2000, p. 213).

The narrative text in phenomenological research also provides cognitive meaning that is described as informational, conceptual, expository and designative (Van der Zalm & Bergum, 2000). The findings of this study also bring to light many pragmatic considerations for nursing practice:

- (1) Nurses and other health professionals need to be familiar with the population of individuals at risk for chronic respiratory failure, and they need to know how symptoms manifest. Proactive teaching should be provided to those at risk, including family and significant others, in order to assist them in seeking assistance in a timely manner.

- (2) Nurses and other health professionals need to develop an understanding of the universal properties of transition. Through this understanding they need to assist individuals and families to integrate technology into their way of being by exploring the individual's goals and plans, and by assisting them to access appropriate resources in a timely manner. Nurses need to develop ways of conveying a hopeful future to VAIs and their families.
- (3) Nurses and other health professionals need to assess potential barriers to self-determination. Interventions that respect self-determination and foster autonomy are essential.
- (4) Nurses and other health professionals need to ensure that non-vocal ventilated individuals are provided with timely and effective means of communication.
- (5) Nurses and other health professionals need to work to integrate a system of care that bridges hospital and home, and confines hospital length of stay to a period of time that is based on medical need.
- (6) Nurses and other professionals need to recognize the importance of involving family members in all aspects of care and planning during transition to LTMV. Diverse resources for family members should be available in order to assist them in coping with transition to LTMV.

Recommendations for Education

The implications for education, with respect to the findings of this study, include the enhancement of student knowledge and understanding of populations at risk for CRF, the symptom manifestation and experience of CRF and strategies to manage CRF. In

addition, students of nursing need to develop an understanding of the complex process of transition as this may assist them in valuing and recognizing the need for psychosocial intervention.

In an evidence-based culture, nursing students need to understand the breadth of the role that nurses, nursing research and nursing knowledge play in the health and wellbeing of individuals and families. They need to be consumers of all knowledge that is relevant to health and wellbeing; however, students of nursing need to be particularly aware of resources and clinical learning opportunities that help them to develop an understanding of their role as a nurse.

Gaining an understanding of individual and family lived experience assists nurses in developing a patient-centered approach to care. Thus efforts to expose nursing students to such knowledge and assist them in recognizing its relevance to nursing practice are essential.

Nurse leaders need to support the educational needs of nurses who care for ventilated clients throughout the healthcare continuum. Nurses, by virtue of the time they spend with clients, are in a key position to coordinate, coach, validate and facilitate transition. However, nurses require support and validation for the diversity of their role as “care” providers.

Recommendations for Research

Upon reviewing the questions that were posed throughout the discussion of findings, several areas were identified as requiring further study:

- 1) Epidemiological exploration of long-term ventilator utilization in Canada.
- 2) Barriers and facilitators to the timely home discharge of ventilated individuals.

- 3) Health professional views and practices regarding decision making by individuals with communication challenges and altered mental state.
- 4) The family caregiver experience of decision-making.
- 5) Exploration of issues related to symptom manifestation and timing of ventilation from the perspective of individuals living with CRF.
- 6) Exploration of what it is like for nurses and other health professionals to care for individuals transitioning to LTMV.
- 7) Exploration of the experience of life in a LTC facility for individuals on LTMV.
- 8) Longitudinal exploration of families' experiences of barriers and facilitators to the integration of their role as primary caregiver.
- 9) Intervention studies to diminish health professional and family knowledge deficit, anxiety and fear regarding LTMV.

Conclusion

This phenomenological study has looked at the lived experiences of individuals requiring mechanical ventilation and their family caregivers as they transitioned to living life with a reliance on LTMV. All participants revealed that the essence of their experience involved sustaining self and sustaining family as they worked to integrate ventilator technology into their way of being. Individuals requiring mechanical ventilation reclaimed the energy and vitality that had been subsumed by the tyrannical symptoms of CRF, and they moved forward with a renewed sense of self. Family caregivers adopted vigilance as a new way of being and they also viewed life as going on.

This chapter presented the discussion of the findings. Study limitations and the appropriateness of the methodological approach were presented. Recommendations for

nursing practice, education and future research were suggested.

Reflection

The journey to completion of this thesis has been both demanding and meaningful. In phenomenological research, the researcher is the tool through which the text is interpreted and lived experience is illuminated. Therefore the researcher bears a significant responsibility for the story. To my surprise, the “letting go” of this personal and professional journey has been difficult. In the mid-1930s, the novelist James Agee documented the story of the lives of three southern sharecropper families. His words resonate with my thoughts and fears about the completion of this journey:

To come devotedly into the depths of a subject, your respect for it increasing in every step and your whole heart weakening apart with shame upon yourself in your dealing with it: To know at length better and better and at length into the bottom of your soul your unworthiness of it . . . (1969, p.319).

As I came to understand the experience of transition through the stories of the participants in this study, I was filled with awe and wonder. Yet, I am reminded of the sanguine words of Bob, Rose and Paul:

We aren't all like Christopher Reeve or Rick Hansen. We don't want people to think that we are superhuman. We just want to be ordinary and live our lives like everyone else.

My dream was to be what most people strive to be . . . To be able to contribute.

I was out there to prove to this world, you know, this guy can have a lot of disabilities but he also has a lot of abilities.

In the end, as in the beginning, I am reminded that the phenomenon of interest was lived human experience, whole and in context. I am most grateful that it was!

The words that were so long ago typed onto a computer are now filled with meaning;
“inquiry changes the researcher” . . . indeed it does.

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APPENDICES

- APPENDIX A: Human ethics approval: University of Manitoba Education and Nursing Research Ethics Board (ENREB)
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- APPENDIX C: Formal information Letter for: (1) Nurses in the Respiratory Outpatient Clinic and (2) Allied health professionals in the LTC facility.
- APPENDIX D: Sample eligibility criteria
- APPENDIX E: Script: Preliminary study information. (Read to potential ventilator user participants).
- APPENDIX F: Preliminary study information letter. Mailed to potential ventilator user participants.
- APPENDIX G: Investigator script (telephone & in-person)-providing further study information to interested potential ventilator user participants.
- APPENDIX H: Consent form: Ventilator user
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APPENDIX A
ENREB Approval

APPROVAL CERTIFICATE

04 May 2006

TO: Winnifred Briscoe

Principal Investigator

(Advisor R.
Woodgate)

FROM: Stan Straw, Chair
Education/Nursing Research Ethics Board (ENREB)

Re: Protocol #E2006:043
"Transition to Long term Mechanical Ventilation: The Lived
Experience of Individuals with Chronic Respiratory Failure and their
Family Caregivers"

Please be advised that your above-referenced protocol has received human ethics approval by the **Education/Nursing Research Ethics Board**, which is organized and operates according to the Tri-Council Policy Statement. This approval is valid for one year only.

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.

Please note:

- if you have funds pending human ethics approval, the auditor requires that you submit a copy of this Approval Certificate to **Kathryn Bartmanovich, Research Grants & Contract Services (fax 261-0325)**, including the Sponsor name, before your account can be opened.
- if you have received multi-year funding for this research, responsibility lies with you to apply for and obtain Renewal Approval at the expiry of the initial one-year approval; otherwise the account will be locked.

Appendix B**Initial Information Letter for Nurses in RSOPD**

Dear _____:

I am currently a nurse and a student in the Master of Nursing Program at the University of Manitoba. I am writing to inform you of a research study that I am commencing to complete the Master of Nursing Program. The study is supervised by Dr. Roberta Woodgate, Assistant Professor in the Faculty of Nursing at the University of Manitoba. Other thesis committee members are Dr. Wanda Chernomas from the University of Manitoba, Faculty of Nursing and Dr. Elani Giannouli, Department of Internal Medicine. The research project is titled: *Transition to Long Term Mechanical Ventilation: The Lived Experience of Individuals with Chronic Respiratory Failure and their Family Caregivers*. For this study I will be interviewing ventilator users and family caregivers.

I would very much appreciate meeting with you, at your earliest convenience, in order to provide you with more information about the study. I anticipate that our meeting will require ten to thirty minutes of your time. Please call _____ or email _____ and _____.

I look forward to hearing from you.

Sincerely,

Winn Briscoe RN, BN
Master of Nursing Student

Appendix C

Information Letter for Nurses: Study and Eligibility Criteria (page one of two)

Project Title: Transition to Long Term Mechanical Ventilation: The Lived Experience of Individuals with Chronic Respiratory Failure and their Family Caregivers

As little is known about the transition experiences of those requiring LTMV, the purpose of this qualitative, phenomenological research thesis is to gain an in-depth understanding of the individual and caregiver perspectives of the experience of transition to LTMV. The questions that guide this study are:

- 1) How do individuals with chronic respiratory failure experience transition to LTMV?
- 2) How is transition to LTMV experienced by family caregivers?
- 3) What are the similarities and differences in the meaning of the transition experience for individuals with chronic respiratory failure and their family caregivers?

PARTICIPANT SAMPLE:

For this study, *five to ten participants on LTMV and five to ten family caregivers* will be interviewed over a six month period.

ELIGIBILITY CRITERIA

Ventilator User:

- Male and female individuals who have experienced chronic respiratory failure, and require the utilization of long term mechanical ventilation (invasive or non-invasive) for *greater than six consecutive hours per 24 hour period*
- Potential participants must also *speak and read English*. (May use communication assistance devices to speak)
- Potential participants must be *eighteen years of age or older*
- Persons on continuous positive airway pressure (CPAP) for obstructive sleep apnea will *not* be eligible to participate.

Caregivers:

- Family caregivers are persons, often related to the ventilator user, who provide unpaid care for the ventilator user. They need not be the sole caregiver or the primary caregiver.
- *Family caregivers of persons who meet the above eligibility criteria, and consent to participate in the study will also be invited to participate. Caregivers must also be 18 years of age and speak and read English.*

Appendix C

Information Letter for Nurses: Study and Eligibility Criteria (page two of two)

RECRUITMENT PROCEDURES:

Potential participants for this study will not be approached by the investigator until they indicate that they are interested in hearing more about the study. Therefore, an invitation to participate must be provided by an individual who has no involvement with the study.

Thank-you for your assistance in informing potential participants about this study. Once you are clear regarding the eligibility criteria, I would ask that you:

- Provide potential participants that attend clinic with initial study information by reading the script provided (*see attached*).

If an individual is interested in hearing more information about the study:

- They can contact me directly per contact information provided on script.

OR//

- Upon providing you with verbal permission to release their name, please notify me with their name and phone number. I will call them and if they agree to participate, they will then be required to provide formal consent.
- *For ventilator users who do not attend clinic on a regular basis, I would ask that you please identify them and address the stamped envelopes provided.
- **It is important for all potential participants to be aware that their participation is entirely voluntary and their care will be unaffected by either their participation or refusal in the study.

Every effort will be made to provide participants with privacy and confidentiality. Thank-you very much for your assistance. Please call or email me with any questions or the need for clarification.

Sincerely,

Winn Briscoe RN, BN

Master of Nursing Student

Appendix D
Sample Criteria

PARTICIPANT SAMPLE:

For this study, *five to ten participants on LTMV and five to ten family caregivers* will be interviewed over a six month period.

ELIGIBILITY CRITERIA

Ventilator User:

- Male and female individuals who have experienced chronic respiratory failure, and require the utilization of long term mechanical ventilation (invasive or non-invasive) for *greater than six consecutive hours per 24 hour period*
- Potential participants must also *speak and read English*
- Potential participants must be *eighteen years of age or older*
- Persons on continuous positive airway pressure (CPAP) for obstructive sleep apnea will *not* be eligible to participate.

Caregivers:

- Family caregivers are persons, often related to the ventilator user, who provide unpaid care for the ventilator user. They need not be the sole caregiver or the primary caregiver.
- *Family caregivers of persons who meet the above eligibility criteria, and consent to participate in the study will also be invited to participate. Caregivers must also be 18 years of age and speak and read English.*

Appendix E**Nurses Script for Potential Ventilator User Participants**

Dear (Ventilator user),

My name is Winn Briscoe, and I am a student in the Master of Nursing Program at the University of Manitoba. To complete my program, I am doing a research project about what it is like to be a ventilator user and what it was like to adjust to using the ventilator every day. I believe that a better understanding of the experience of being a ventilator assisted individual may help nurses and other health care professionals to provide improved care.

It is my intention to interview a small group of ventilator users and a small group of family caregivers. Each ventilator user will be interviewed one to two times and the interview will be audio tape-recorded. The identity of any ventilator user or family caregiver will be kept confidential. After interviewing, I will put the information together and write up the results. You will be provided with a finalized summary of the study if you would like one. **No one in clinic will know whether or not you decide to participate in this study.**

Please tell the person reviewing this information with you whether *you would or would not like to hear more about the study.* If you are interested, they will give you this contact sheet and you can call me directly **OR** I can call you if you give the nurse clinician permission to release your name to me. If you decide to participate after talking to me, we will set up an interview at a time and place convenient for you. If you decide not to participate, you can say no without any problem. Participation is entirely voluntary. Thank-you for considering this information.

Yours sincerely,

Winn Briscoe RN, BN

Master of Nursing Student

University of Manitoba: **CONTACT _____ or e-mail**

Appendix F

Preliminary information letter -Resident of Respiratory Unit in Long-term Care Facility

Dear Ventilator user,

My name is Winn Briscoe, and I am a student in the Master of Nursing Program at the University of Manitoba. To complete my program, I am doing a research project about what it is like to be assisted by a ventilator and what it was like to adjust to using the ventilator every day. I believe that a better understanding of the experience of being ventilator dependent may help nurses and other health care professionals to provide improved care.

It is my intention to interview a small group of ventilator users and a small group of their family caregivers. Each ventilator user will be interviewed one to two times for about one to two hours, and the interviews will be tape-recorded. The identity of any ventilator user or family caregiver who participates will be kept confidential. After interviewing, I will put the information together and write up the results. You will be provided with a finalized summary of the study if you would like one.

Please tell the person reviewing this information with you whether *you would or would not like to hear more about the study*. If you are interested, you can call me directly at the number on this paper, **OR/**, if you give _____ (Nurse Manager) permission to release your name to me, I will call you, **and** if you prefer, I will come to the respiratory unit where you reside to tell you more about it. If you do decide to participate after talking to me, we will set up an interview at a time and in a private place, convenient for you. If you decide not to participate, you can say no without any problem. Participation is entirely voluntary. No one on your unit will be told by me whether or not you decide to participate in this study.

Thank-you for considering this information.

Yours sincerely,

Winn Briscoe RN, BN

Master of Nursing Student. CONTACT: _____ or email _____

University of Manitoba

Appendix F (Page one of two)

Dear Ventilator user,

My name is Winn Briscoe, and I am a student in the Master of Nursing Program at the University of Manitoba. To complete my program, I am doing a research project about what it is like to be assisted by a ventilator and what it was like to adjust to using the ventilator every day. I believe that a better understanding of the experience of being a ventilator assisted individual may help nurses and other health care professionals to provide improved care.

It is my intention to interview a small group of ventilator users and a small group of their family caregivers. Each ventilator user will be interviewed one to two times for one to two hours, and the interviews will be tape-recorded. The identity of any ventilator user or family caregiver who participates will be kept confidential. After interviewing, I will put the information together and write up the results. You will be provided with a finalized summary of the study if you would like one. No one in clinic will know whether or not you decide to participate in this study.

If, after reviewing this information, you decide you would like to hear more about the study, you can contact me directly using the contact information on this letter,

OR/ you can check the box on page two and return it in the enclosed, stamped and self-addressed envelope. If you are interested, please provide your name and phone number and I will call and tell you more about the study.

If you decide to participate after talking to me, we will set up an interview at a time and place convenient for you. If you decide not to participate, you can say no without any problem. Participation is entirely voluntary.

Thank-you for considering this information.

Yours sincerely,

Winn Briscoe RN, BN
Master of Nursing Student
University of Manitoba

Appendix F (Page two of two)

Please contact me directly at Winn Briscoe _____ or email

Or/

If you would prefer that I to contact you, please include your name and phone number and return this response in the self-addressed, stamped envelope provided.

I would be interested in hearing more about the study.

NAME: _____

Telephone number _____

Thank-you

Appendix G**Investigator Script: Ventilator-User (telephone and in-person). (Page one of two)**

Hello _____

My name is Winn Briscoe, and I am a student in the Master of Nursing program at the University of Manitoba. I have been told by _____ from _____ that you have received some information about a study I am doing and are willing to hear more about it.

OR/

I received your response from the information letter about my study.

I am a nurse and I have cared for people who use long term mechanical ventilation. I am interested in ventilator user's initial experiences of being mechanically ventilated and adjusting to long term ventilation. There is not a lot written about how one experiences the change or adjustment to being mechanically ventilated. I believe that nurses and other health care professionals, who care for persons new to mechanical ventilation, need to understand as much as we can about what it is like to experience this change.

For this study, I have chosen to interview ventilator users and their family caregivers. Those who agree to participate will be interviewed one to two times. Each interview may last one to 2.5 hours. The interviews will be done at a time and place convenient to each participant. The interviews will be audio tape-recorded so that I do not miss any important information.

A transcriber will type the interviews, and then I will read them and look at them for common issues and concerns. Dr. Roberta Woodgate from the University of Manitoba will supervise my work and she will be the only other individual with access to the audio-taped interviews. All names will be removed from the transcribed interviews and will be replaced with a code. The tapes and transcripts will be stored securely and destroyed when no longer required. No one in clinic will know whether or not you decide to participate in this study.

The information I get from the interviews will be written up for my thesis. It is also my intention to publish the study in a professional journal and present it at a professional meeting. I want to share the information with other nurses and health care workers, but at no time will you be named. If you are interested in receiving a summary of the study, it will be provided to you after completion.

Appendix G

Investigator Script (telephone and in-person). (Page two of two)

If you agree to participate, you can drop out of the study at any time, ask to stop the interview at any point, or refuse to answer any question without any problem.

Are there any questions you would like to ask about the study?

Do you think you would like to be a part of the study?

- **(If “no”)** Thank-you very much for your time. I sincerely appreciate having had the opportunity to speak with you.
- **(If “I would like to think about it”)** I would certainly appreciate you doing that. When should I call you back to get your decision?
- **(If “yes”)** Thank-you for your interest. When would be a good time to do the first interview? Would you like to do it at your home (either in community residence or in long-term care facility)? **(If “no”)** Where would you like to do it? Would you like me to arrange for a private meeting room on your clinic day? Would you like to pick another place?

When we meet, I will ask you to sign a consent form saying you will participate based on the information I have given you, and I will ask you to fill out some forms for background information about you. The forms will take approximately 10-15 minutes to complete.

For the interview, it may be helpful to think about your first experiences when you were in the hospital, adjusting to being ventilated. I am interested in your thoughts, ideas and views about what it was like for you to adjust physically and psychologically to requiring a ventilator. This may include remembering things that helped, got in the way, or made things more difficult.

Thank-you for your time, I will look forward to meeting you on _____ at _____.

Any questions arising from this conversation will be answered and noted on the front and back of this sheet

*NOTE: *Will be typed on U of M letterhead).*

Appendix H: INFORMED CONSENT Ventilator User (page 1 of 2)

Research Project Title: Transitioning to Long Term Mechanical Ventilation: The Lived Experience of Individuals with Chronic Respiratory Failure and their Caregivers

Study Researchers: Winn Briscoe, Master of Nursing Student at the University of Manitoba Faculty of Nursing. **Thesis Committee Members:** **Supervisor:** Dr. Roberta Woodgate. **Internal Examiner:** Dr. Wanda Chernomas. **External Member:** Dr. Elani Giannouli

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

I, _____, agree to participate in the above study. I have been told that the purpose of the study is to gain an understanding of what it is like to adjust or transition to the use of long term mechanical ventilation as a ventilator user or as an informal caregiver. I understand that ventilator users who live in the community, or in long term care facilities, and their informal caregivers will be asked to participate.

I understand that if I agree to participate in this study, I would be asked to participate in one to two tape-recorded interviews that are expected to take one to 2 1/2 hours to complete. During the interview I will be asked questions about my experience adjusting and transitioning to the ventilator. I understand that although two interviews have been planned, I may decline the second interview. I will also be asked to complete a demographic and health information questionnaire and a health survey. These forms should take about 10-15 minutes to complete. If I have difficulty writing, I understand that I can dictate my responses to the researcher.

I understand that my participation in the study is completely voluntary. I understand that the physicians and other professionals who care for me will not know that I decided to take part in the study. I understand that I may withdraw at any time and/or refrain from answering any questions without consequence.

I understand that there are no direct benefits for me to participate in the study. However, I understand that this study will result in knowledge about what it is like to adjust to being a long term ventilator user and what it is like to be an informal caregiver of an individual adjusting to long term ventilator use. This knowledge may provide professionals with guidance about how to better assist long term ventilator users and informal caregivers during the transition to ventilation.

I understand that there are no undue risks to me in participating in the study. However, I am aware that having the opportunity to talk about my experiences with adjustment to long term mechanical ventilation may make me more aware of some of my feelings. If I become very upset or if I need to talk to someone about my feelings, I understand that I can contact the researcher.

Appendix H: INFORMED CONSENT (page 2 of 2)

understand that findings from this study may be presented at a health conference or professional meeting or published in a professional journal. In all instances, my family's identity and my name would not be revealed to anyone. I am aware that information may be altered in order to decrease the likelihood that I or my family may be identified. I am also aware that my name will be replaced with a code number so that no one will be able to identify us. I understand that confidentiality will be maintained except in situations in which there is a legal requirement to disclose identity (i.e. abuse situations). I understand that all data, including the audiotapes, interview transcripts, researcher's notes, and demographic and health information, will be stored in a locked filing cabinet and computer protected by a password known only to Winn Briscoe and Dr. Roberta Woodgate. I understand that all data will be destroyed seven years following completion of the study.

understand that if I decide to participate in the study, a summary of the study will be provided to me if requested.

My signature on this form indicates that I have understood to my satisfaction the information regarding participation in the research project and agree to participate as a subject. I understand that my continued participation should be as informed as my initial consent, so I should feel free to ask for clarification or new information throughout my participation. I understand that I may contact Winn Briscoe () or Dr. Roberta Woodgate (204-474-8338) if I have concerns, questions or need additional information.

understand that this research has been approved by the Education/Nursing Research Ethics Board at the University of Manitoba; the Health Sciences Centre, Winnipeg, Manitoba; and Riverview Health Centre, Winnipeg, Manitoba. If I have any concerns or complaints about this project, I may contact any of the above-named persons or the Human Ethics Secretariat at 204-474-7122 or e-mail margaret_bowman@umanitoba.ca. A copy of this consent form has been given to me to keep for my records and reference.

_____ Signature of Researcher	_____ Signature of Participant	_____ DATE
.....		

would like a summary report of the findings:

YES NO
 Please mail a summary of the report of findings to: Name _____
 Address: _____ Postal Code: _____

Appendix I**Preliminary study information letter-Potential caregiver participants. (Page one of two)**

Dear Caregiver,

My name is Winn Briscoe, and I am a student in the Master of Nursing Program at the University of Manitoba. To complete my program, I am doing a research project about what it is like to be a ventilator assisted individual, and what it was like to adjust to using the ventilator every day. I am also studying what it is like to care for family members who are using mechanical ventilation. I believe that a better understanding of ventilator dependence may help nurses and other health care professionals to provide improved care.

It is my intention to interview a small group of ventilator users and a small group of family caregivers. Each family caregiver will be interviewed one to two times for one-two hours, and the interviews will be tape-recorded. The identity of any ventilator user or family caregiver will be kept confidential. After interviewing, I will put the information together and write up the results. You will be given an opportunity to review the information and you will be provided with a finalized summary of the study if you would like one. No one in clinic will know whether or not you decide to participate in this study.

If, after reviewing this information, you decide you would like to hear more about the study, contact me directly using the contact information provided in this letter, **OR/** check the box on page two and return it in the enclosed, stamped and self-addressed envelope. If you are interested, please provide your name and phone number and I will call and tell you more about the study. If you decide to participate after talking to me, we will set up an interview at a time and place convenient for you. If you decide not to participate, you can say no without any problem. Participation is entirely voluntary.

Thank-you for considering this information.

Yours sincerely,

Winn Briscoe RN, BN

Master of Nursing Student

University of Manitoba

Appendix I

Preliminary study information letter-Potential Caregiver Participants. (Page two of two)

Please contact me directly at Winn Briscoe : _____ or email

Or/

If you would prefer that I to contact you, please include your name and phone number and return this response in the self-addressed, stamped envelope provided.

I would be interested in hearing more about the study.

NAME: _____

My phone number where I can be reached _____

Thank-you

Appendix J

Investigator Script-provides further study information to interested caregiver participants. (Page one of two)

Hello _____

My name is Winn Briscoe, and I am a student in the Master of Nursing program at the University of Manitoba. I have been told by _____ from _____ that you have received some information about a study I am doing and are willing to hear more about it.

OR/

I received your response from the information letter about my study.

I am a nurse and I have cared for people who use long term mechanical ventilation. I am interested in exploring ventilator user's initial experiences of being mechanically ventilated. There is not a lot written about how one experiences the change or adjustment to being mechanically ventilated. There is also not a lot written about family caregiver's experience of caring for a family member who becomes a ventilator user, therefore I am also interested in learning about what it is like to be a family caregiver of a ventilator user. Family caregivers are persons, who may or may not be related to the ventilator user, who provide unpaid care. A family caregiver need not be the only caregiver or the primary caregiver. I believe that nurses and other health care professionals, who care for persons new to mechanical ventilation, need to understand as much as possible about what it is like for clients and family members to experience this change.

For this study, I have chosen to interview ventilator users and their family caregivers. Those who agree to participate will be interviewed one to two times. Each interview may last from one to 2.5 hours. The interviews will be done at a time and place convenient to each participant. The interviews will be tape-recorded so that I do not miss any important information.

A transcriber will type the interviews, and then I will read them and look at them for common issues and concerns. Drs. Roberta Woodgate from the University of Manitoba will supervise my work and she will be the only other person with access to the audio taped interviews. All names will be removed from the transcribed interviews and will be replaced with a code. The tapes and transcripts will be stored securely and destroyed when no longer required.

Appendix J

Investigator Script (telephone and in-person). (Page two of two)

If you agree to participate, you can drop out of the study at any time, ask to stop the interview at any point, or refuse to answer any question without any problem.

Are there any questions you would like to ask about the study?

Do you think you would like to be a part of the study?

- (If “no”) Thank-you very much for your time. I sincerely appreciate having had the opportunity to speak with you.
- (If “I would like to think about it”) I would certainly appreciate you doing that. When should I call you back to get your decision?
- (If “yes”) Thank-you for your interest. When would be a good time to do the first interview? Would you like to do it at your home (either in community residence or in long-term care facility)? (If “no”) Where would you like to do it? Would you like me to arrange for a private meeting room on your clinic day? Would you like to pick another place?

When we meet, I will ask you to sign a consent form saying you will participate based on the information I have given you, and I will ask you to fill out some forms for background information about you. The forms will take approximately 10-15 minutes to complete.

For the interview, it may be helpful to think about your first experiences when you were in the hospital, adjusting to being ventilated. I am interested in your thoughts, ideas and views about what it was like for you to adjust physically and psychologically to requiring a ventilator. This may include remembering things that helped, got in the way, or made things more difficult.

Thank-you for your time, I will look forward to meeting you on _____ at _____.

Any questions arising from this conversation will be answered and noted on the front and back of this sheet

(NOTE: * Will be typed on U of M letterhead).

Appendix K: INFORMED CONSENT Caregiver

Research Project Title: Transitioning to Long Term Mechanical Ventilation: The Lived Experience of Individuals with Chronic Respiratory Failure and their Caregivers

Study Researchers: Winn Briscoe, Master of Nursing Student at the University of Manitoba Faculty of Nursing. **Thesis Committee Members:** **Supervisor:** Dr. Roberta Woodgate. **Internal Examiner:** Dr. Wanda Chernomas. **External Member:** Dr. Elani Giannouli

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

_____, agree to participate in the above study. I have been told that the purpose of the study is to gain an understanding of what it is like to adjust or transition to the use of long term mechanical ventilation as a ventilator user or as an informal caregiver. I understand that ventilator users who live in the community, or in long term care facilities, and their informal caregivers will be asked to participate.

I understand that if I agree to participate in this study, I would be asked to participate in one to two tape-recorded interviews that are expected to take one to 2 1/2 hours to complete. During the interview I will be asked questions about my experience adjusting and transitioning to the ventilator. I understand that although two interviews have been planned, I may decline the second interview. I will also be asked to complete a demographic and health information questionnaire and a health survey. These forms should take about 10-15 minutes to complete.

I understand that my participation in the study is completely voluntary. I understand that the physicians and other professionals who care for me will not know that I decided to take part in the study. I understand that I may withdraw at any time and/or refrain from answering any questions without consequence.

I understand that there are no direct benefits for me to participate in the study. However, I understand that this study will result in knowledge about what it is like to adjust to being a long term ventilator user and what it is like to be an informal caregiver of an individual adjusting to long term ventilator use. This knowledge may provide professionals with guidance about how to better assist long term ventilator users and informal caregivers during the transition to ventilation.

I understand that there are no undue risks to me in participating in the study. However, I am aware that having the opportunity to talk about my experiences with adjustment to long term mechanical ventilation may make me more aware of some of my feelings. If I become very upset or if I need to talk to someone about my feelings, I understand that I can contact the researcher.

Appendix K: INFORMED CONSENT (page 2 of 2)

I understand that findings from this study may be presented at a health conference or professional meeting or published in a professional journal. In all instances, my family's identity and my name would not be revealed to anyone. I am aware that information may be altered in order to decrease the likelihood that I or my family may be identified. I am also aware that my name will be replaced with a code number so that no one will be able to identify us. I understand that confidentiality will be maintained except in situations in which there is a legal requirement to disclose identity (i.e. abuse situations). I understand that all data including the audiotapes, interview transcripts, researcher's notes, and demographic and health information, will be stored in a locked filing cabinet and computer protected by a password known only to Winn Briscoe and Dr. Roberta Woodgate. I understand that all data will be destroyed seven years following completion of the study.

I understand that if I decide to participate in the study, a summary of the study will be provided to me if requested.

My signature on this form indicates that I have understood to my satisfaction the information regarding participation in the research project and agree to participate as a subject. I understand that my continued participation should be as informed as my initial consent, so I should feel free to ask for clarification or new information throughout my participation. I understand that I may contact Winn Briscoe () or Dr. Roberta Woodgate (204-474-8338) if I have concerns, questions or need additional information.

I understand that this research has been approved by the Education/Nursing Research Ethics Board at the University of Manitoba; the Health Sciences Centre, Winnipeg, Manitoba; and Riverview Health Centre, Winnipeg, Manitoba. If I have any concerns or complaints about this project, I may contact any of the above-named persons or the Human Ethics Secretariat at 204-474-7122 or e-mail margaret_bowman@umanitoba.ca. A copy of this consent form has been given to me to keep for my records and reference.

Signature of Researcher	Signature of Participant	DATE

.....
would like a summary report of the findings:

YES NO

Please mail a summary of the report of findings to: Name _____

Address: _____ Postal Code: _____

Demographic and Health Questionnaire-Ventilator User. (Page one of three)

LD. No. _____

Date _____

- 1) **Date of Birth** _____
- 2) **Gender:** female _____ male _____
- 3) **Are you married?** _____, **Single?** _____, **Divorced?** _____, **Separated?** _____ **Widowed?** _____.
- 4) **What city or town do you live in?** _____
- 5) **Where do you live (e.g. house, long-term care facility, assisted living facility)** _____
- 6) **If you live with other persons, please describe your relationship to them**

- 7) **How long have you been living at your present residence?** _____
- 8) **Were you living at your present residence before you had the breathing problems (respiratory failure) that required you to be hospitalized and put on LTMV?**
) **YES** _____ **NO** _____
- 9) **If no, where did you live prior to requiring LTMV?**

- 10) **Ethnic background**
 Canadian _____ Aboriginal/First Nation/Inuit _____ East Indian _____ African American _____
 SA _____ Jewish _____ Middle Eastern _____ European _____
 Asia & Pacific Islands (Chinese, Japanese, Philipino, Vietnamese, Korean).
 Other (SPECIFY) _____ Not sure _____

Appendix L

Demographic form-Ventilator User. (Page two of three)

I.D. No. _____

Date _____

12) What is your family income?

- Below \$10,000/year _____
- \$10,000-\$20,000/year _____
- \$21,000-\$30,000/year _____
- \$31,000-\$40,000/year _____
- \$41,000-\$50,000/year _____
- \$51,000-\$60,000/year _____
- \$61,000-\$70,000/year _____
- over \$70,000/year _____

13) Are you currently employed? YES _____ NO _____

14) If YES, Fulltime? _____ Parttime? _____

15) If YES, What is your job?

15) If NO, has the use of LTMV affected your employment status? YES _____ NO _____
If so, how has it affected your employment status?

6) What kind of mechanical ventilator support are you using?

7) Did you ever use another kind(s) of ventilator support? YES _____ NO _____

8) If YES, what kind of ventilator support have you used in the past.

9) Do you require oxygen? YES _____ NO _____

10) If YES. Describe how much oxygen you require and how frequently you use it
Oxygen litres/minute _____ . Frequency used _____

11) Do you have home care assistance?

Appendix L

Demographic form-Ventilator User. (Page three of three)

22) If so, how many hours/day do you require their assistance?

23) Is there a family member or someone else, who is unpaid, that you consider to be your caregiver?

24) Is there anything else you would like to tell me about yourself?

Thank-you

Appendix M**Demographic and Health Questionnaire: Caregiver Participant. (Page one of two)**

I.D. No. _____

Date _____

1) *What is your relationship to* _____ ?

_____2) *What is your date of birth?* _____3) *Gender:* female _____ male _____4) *Are you married?* _____, *Single?* _____, *Divorced?* _____,
Separated? _____ *Widowed?* _____.5) *What city or town do you live in?* _____6) *What is your family income?*

<i>Below \$10,000/year</i>	_____
<i>\$10,000-\$20,000/year</i>	_____
<i>\$21,000-\$30,000/year</i>	_____
<i>\$31,000-\$40,000/year</i>	_____
<i>\$41,000-\$50,000/year</i>	_____
<i>\$51,000-\$60,000/year</i>	_____
<i>\$61,000-\$70,000/year</i>	_____
<i>Over \$70,000/year</i>	_____

7) **Ethnic background**

Canadian _____ Aboriginal/First Nation/Inuit _____ East Indian _____ African American _____
 USA _____ Jewish _____ Middle Eastern _____ European _____
 Asia & Pacific Islands (*Chinese, Japanese, Philipino, Vietnamese, Korean*). _____
 Other (SPECIFY) _____ Not sure _____

8) *Are you currently employed outside of the home?* YES _____ NO _____

Appendix M
Demographic and Health Forms: Caregiver participant. (Page two of four)

9) If YES, Fulltime? _____ . Part-time? _____

10) If YES, What is your job?

11) Has the use of LTMV affected your employment status? YES _____ NO _____

12) If yes, how has your employment status been affected??

13) Did your income change when _____ began LTMV?

YES _____ NO _____

14) If YES. Describe how your income changed

15) Do you presently live with _____ ? YES _____ NO _____

16) How many hours of care /day do you provide? _____

17) Describe the care that you provide for _____ .

18) Who else cares for _____ ?

19) Describe the care provided to _____ by others.

20) Is there anything else you would like to tell me about yourself?

Thank-you

Appendix O

Interview Guide-Ventilator user

1. Can you please tell me a little about yourself and the time when you first experienced breathing problems?
Probes: Do you remember the first time you experienced breathing problems? What did it feel like? How did it affect you and your daily life?
 2. Can you please tell me about the time just before you needed mechanical ventilation?
Probes: How different was your breathing compared to the first time you encountered breathing problems? What was life like for you then?
 3. Can you please tell me about the time when the ventilator was first introduced to you?
Probes: Do you remember how it was introduced? If 'yes', please explain (e.g., who explained it to you, what reasons were provided etc.).
 What do you remember most about that time? When you were first introduced to it, what thoughts were going through your head?
 4. Can you please tell me what it was like for you when you were initially put on the ventilator?
Probe: What do you remember most about that time? What did it feel like?
 What initial impact did it have on your life? What helped (or did not help) you during this period?
 5. What was it like to get used to mechanical ventilation?
Probe: Do you feel you are used to it? Please explain.
 What did getting used to ventilations feel like physically? Were there also emotional or psychological aspects to being on a ventilator that you had to get used to? What do you remember most about that adjustment?
- What has life been like for you since being put on the ventilator?
- Some people would consider getting used to using a ventilator everyday as a major transition or life event. Do you see using a ventilator as a major transition in your life? Please explain.
- Probes:** How different is it to other transitions that you have experienced? Please explain.
- What advice would you offer to people with breathing problems/respiratory failure who are in the hospital or at home, and are new to the experience of LTMV?
- Probes:** What advice would you give to them that would help to get them through it?
- What advice would you offer health professionals that would help them to better care for people who require MV?
- Probes:** What helped you? Was there anything health care providers said or did that made the time more difficult?
- Probes**
- i. What was the most difficult part of the experience?
 - ii. What do you think contributed to your adjustment?

Appendix P**Interview Guide-Caregiver participant. (Page one of two)**

- 1) Would you please tell me a little bit about yourself and your relationship to (VAI)?
- 2) Would you please tell me what you remember about VAI's breathing problems before he/she used mechanical ventilation?
Probes: What were those times like for you?
- 3) Please tell me about what it was like for you and (VAI) during the time just before mechanical ventilation was introduced.
Probes: How different were your lives at that time compared to the previous times that (VAI) had encountered breathing problems? What was life like for you then?
- 4) Can you please tell me about the time when the ventilator was first introduced to you and (VAI).
Probes: Do you remember how it was introduced to? If 'yes', please explain (e.g., who explained it to you, reasons provided etc.).
What do you remember most about that time? When (VAI) was first introduced to it, what thoughts were going through your head?
- 5) Can you please tell me what it was like for you when (VAI) was initially put on the ventilator?
Probe: What do you remember most about that time? What initial impact did it have on your life and the life of VAI? What thoughts do you remember having during that time?
- 6) What do you remember about the time when (VAI) was getting use to mechanical ventilation?
Probe: Do you feel (he/she) is used to it? Please explain. Do you feel that you are used to it? Please explain.
- 7) What has life been like for you since (VAI) was put on the ventilator?
- 4) Some people consider the adjustment to long term ventilator use to be a major life transition. Do you see the adjustment as a major transition? How do you see it compared with other transitions you have experienced?
- 5) How would you describe the experience of being with (VAI) in hospital as he/she and you adjusted to LTMV?
Probes
 - a. What was the most difficult part of the experience?
 - b. What do you think contributed to your adjustment?

Appendix P
Interview Guide-Caregiver participant. (Page two of two)

- 6) What was it like for you when you began to provide more care for _____?
Probes: What were your concerns? What were your fears?
- 7) Did anything or anyone help you to feel confident about your ability to care for _____? Please tell me more about that.
- 8) What do you think health care providers really need to know about what it is like to be a family caregiver of a person on a ventilator?
Probe: What advice would you offer to professionals to better assist them in helping family caregivers of persons with respiratory failure?
- 9) What advice would you offer family caregivers that would help them to better care for a family member who requires LTMV?

Other Probes

- Tell me more about that.
- Could you describe what how you felt at that time.
- Go on.
- Non-verbal: nodding.